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UNIVERSITY OF ALBERTA

COPING WITH VISIBLE DISABILITY - PERCEPTIONS OF YOUNG ADULTS

A SYSTEMS THEORY APPROACH

BY

GILLIAN G. RENNIE

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education.

IN

SPECIAL EDUCATION

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

Spring, 1992

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UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Coping With Visible Disability - Perceptions of Young Adults A Systems Theory Approach submitted by Gillian G. Rennie in partial fulfillment of the requirements for the degree of Master of Education in Special Education.

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Dr. B. Schwartz

24 March 1992

This study is dedicated to my parents, Alan and Doreen, for their support and encouraging me to be my best, and that I understand it was very hard for them to let me wheel on my own.

ABSTRACT

This study investigated the perceptions of visibly different adults, and how they have coped with their handicapping conditions in everyday life. For the purpose of this study visible difference has been defined as a physical impairment which is visible. The informants for this study were seven adults, in their twenties to forties, who have had a visible difference either since birth or with onset before or during adolescence. Perceptions were categorized in six systems; individual, family, education, medical and related services, employment and social group. The individual and family systems appeared to be most important in the healthy development of coping abilities. The role of the family is thought to be vital to the integration of the visibly different person. The informants in this study believed that their families were helpful in some way with their integration. It appears that the education system has also been central in the integration of the visibly different individual. A major period of difficulty with integration in the education system appeared to be during the junior high school years, with feelings of nonacceptance from other students. The medical and related services system appears to be perceived as the least important in the healthy development of coping abilities. The informants discussed poor experiences with medical and related services personnel, although they believed that certain professionals were more helpful than others. Implications are discussed for the systems and some suggestions made for counsellors working with visibly different individuals and their families. Families at times may need outside counselling to lessen stress related to the handicapped child including possible feelings of guilt. In the education system, counsellors may need to intervene to develop appropriate social interaction among handicapped and nonhandicapped students. Counsellors at the junior and senior high school levels may also guide handicapped students in choosing future careers which they can master academically, can gain access to the necessary training and for which there is a future need. Within the medical and related services system a possible solution to lessen the perceived lack of information being provided by the medical profession would be a

medical liaison worker who could increased the understanding of all individuals involved. In the individual system counsellors may need to guide handicapped individuals who experience periodic losses of body functions through mourning processes to cope with these losses. Once the grieving is at a manageable level, the counsellor may then help the handicapped individual develop realistic goals and objectives.

I would like to thank Dr. Vargo for his guidance in the initial stage of the study.

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CHAPTER I

INTRODUCTION

General Discussion

In Canada and other developed countries, there are increasing numbers of handicapped persons, as medical procedures improve the survival rates of both infants and those suffering handicaps later in life. At the same time, current policies emphasize the integration of handicapped persons in educational, employment and social settings.

The integration of handicapped persons has become a general concern of professional, family and social groups. At this time, there is a need for professionals, including medical, educational and related personnel and non-professionals including colleagues, family members, employers and classmates to better understand the experiences of handicapped persons.

Statement of the Problem

Literature in this area tends to be from the perspective of the professionals who work with visibly different persons rather than from the handicapped themselves. This lack of information from the handicapped at times may hinder the professionals who are working towards integration of these individuals, in that the professionals may not have adequate knowledge of how best to provide services which will further this process.

A major difficulty in extracting useful information from the studies available is a strong tendency for researchers to use unrealistic groupings. Although the study may be discussing handicapping conditions, these may include such varying conditions as blindness, deafness and having to use a wheelchair. Each of these handicapping conditions has some differences in the difficulties associated with it. Other studies have problems in that they have used instruments to assess such constructs as self-concept or self-esteem, of handicapped persons, with instruments which have not been normed on the handicapped population.

Justification

The reason for using visibly handicapped persons in this study is the probability that they will encounter a maximum number of problems common to disabled people, relating mainly to integration, in such areas as school, employment and social situations.

This study investigates how some visibly different persons cope with their handicapping conditions. In this study, individuals over the age of eighteen were interviewed on their experiences of growing up with a physical handicap. A major difficulty with many of the previous studies done in this area is that there is little information from older individuals who have a long term disability. In this study, visibly different individuals discuss their experiences on living with a handicapping condition from childhood onward.

CHAPTER II

REVIEW OF THE LITERATURE

Literature in this field generally focuses on the perceptions of nondisabled persons who work with the disabled in professional capacities. One national Canadian study which looked at disabled individuals in a wide range of daily activities was the Canadian Health and Disability Survey (1986), compiled from January 1983 to June 1984. This survey examines national data on the prevalence of disability according to the functional definitions of disability and handicap used by the World Health Organization. The questions in the survey allow respondents to identify themselves as having functional limitations in a number of different daily living activities. Results indicate that approximately two-and-a-half million Canadian adults, or twelve percent of the adult population, report some level of disability. In this survey adult population was defined as age fifteen and up. Two-thirds of all disability problems identified in the survey are related to mobility or body movements, fifteen percent to hearing and eight percent to eyesight. Comparing such a range of handicapping conditions can be considered to be a limitation, in that each condition represents a different set of problems. Another limitation in the survey is the age range used in the collection of data. Individuals over the age of sixty-five were incorporated in the tabulation of results, increasing the likelihood of handicapping conditions. Although only twelve percent of the Canadian population is aged sixty-five and over, thirty-seven percent of those reporting a disability fall in this age group. Another limitation with the data collection is that one individual can have different handicapping conditions, such as an older individual's eyesight and level of hearing declining with age. In the tabulation of results this appears as two disabled individuals rather than one person having two handicapping conditions. Because of this a true estimate of the disabled population is still unknown.

Attitudes Toward the Disabled

Social, Educational and Employment Implications

Although visibly different individuals encounter many obstacles in their lives, a major barrier which they must face is the attitude of other people toward them, especially attitudes of family, friends and professionals, in relation to education, medical services and employment. Research has demonstrated that public attitudes toward the disabled reflect educational, vocational and social discriminations and prejudices (Westwood, Vargo & Vargo, 1981). It is hypothesized that how others react to and interact with persons who have visible differences will affect how disabled persons cope with their disabilities later in life.

Within the literature the term 'attitude' has several interpretations. One interpretation, by Fishbein and Ajzen, is that an attitude is "a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (cited in Oskamp, 1977, p. 9). Another definition of attitude is that it has three components: cognitive, affective (emotional) and behavioral. The cognitive component consists "of the ideas and beliefs which the attitude-holder has about the attitude object" (Oskamp, 1977, p. 10). Attitudes toward people with visible differences could include myths and misconceptions about handicapped persons. A second component of attitude is the affective (emotional) area, "the feelings and emotions one has toward the object" (Oskamp, 1977, p. 10), for example, how a nonhandicapped person initially 'feels' on seeing someone with a visible difference. A final component is behavioral, which consists of "one's action tendencies toward the object" (Oskamp, 1977, p. 10).

Physically and/or mentally disabled individuals who bear such labels as mental illness, visible difference or mental handicap may be the targets of prejudice and discriminatory practices. This discrimination may be least apparent in relatively impersonal situations and most blatant in close interpersonal and business situations, such as marriage and employment (Marinelli & Dell Orto, 1977). It would appear that there may be less tolerance of visibly different individuals in areas which in our culture are of critical importance to what is commonly seen as normal functioning.

In the groups regularly interacting with visibly different individuals, the attitudes of teachers, medical practitioners and others, including parents and siblings, can effect the quality of life, self-concept and degree of general acceptance of those individuals by themselves and others (Stewart, 1988). It is important for parents to realize that the visibly different child's basic needs are very similar to those of other children, with some specific needs. This attitude can help the child integrate into everyday life. Overprotection by the family is crippling to initiative, independence and maturity (Barshay, 1964). Equally harmful is the attitude that children are superior when accomplishments are ordinary, which can lead to unrealistic self-concepts.

Attitudes can also effect a visibly different person's right to an education and can influence access, which includes both physical access to the school and access to school programs. For instance, a child who has a visible difference may not be allowed into a public school setting because both the teachers and the parents of other students may believe that the inclusion of the 'special' student into the classroom may disrupt the other students' learning. Education may also be limited by schools not being accessible for someone who uses a wheelchair, or there may be other limitations that would make it a hardship to attend certain schools, such as inappropriate washroom facilities and multi level schools without elevators.

Access to Facilities

Access also effects a visibly different individual's employment possibilities. The individual looking for a job must take into account the working environment and particular needs. The type of work an individual can do may be effected by the handicapping condition. The Canadian Health and Disability Survey indicates that individuals with some type of mobility impairment were less likely to be employed than individuals who had a sensory impairment, such as blindness or hearing loss (Government of Canada, 1986). An employer cannot discriminate against the applicant solely on the visible difference. In 1982 the Government of Canada made an amendment to the Constitution Act, in the area of the Charter of Rights and Freedoms, which states that visible minorities, women, aboriginal people, and people who have either a mental or physical handicap have equal rights under the law (Government of Canada, 1982). This indicates that any of these groups can not be discriminated against on the basis of these differences in applying for a job, and that the best person for that job must be hired. With regard to the visibly different person, if the working environment is inaccessible in some way, then reasonable changes should be made to allow access. Reasonable accommodation, or change, is the adaption of environments, schedules or requirements to the known physical limitations of handicapped persons in a manner that does not impose undue hardship on the employer. Reasonable accommodation may include making facilities readily accessible to and usable by handicapped persons, as well as job restructuring, part-time or modified work schedules, acquisitions or modifications of equipment or devices, and other similar actions (Anderson & Coons, 1979). Inaccessibility is not an acceptable excuse for not hiring a visibly different individual. The Canadian Health and Disability Survey reports that disabled persons appear to be doubly disadvantaged in that they may have functional limitations which may restrict their access to certain types of work, and they may also have lower educational attainment which may also limit their access to work (Government of Canada, 1986).

Creating a barrier-free environment requires modifications of buildings, realignment of attitudes and planning for new programs (Shanhouse & Yates, 1980), to provide independent living for individuals who have visible differences. Independent living is the ability to interact with the environment without assistance from or dependency on external sources, to come and go as one chooses, and to participate or not participate as one chooses (Shanhouse & Yates, 1980). The goal is to provide an environment in which visibly different people have the option of participating fully and interacting totally with society, with choice being the ultimate goal. By designing a barrier-free environment that is esthetically pleasing, the attitudes of both handicapped and nonhandicapped will be positively affected (Shanhouse & Yates, 1980).

Self-Concept

Visible disability often affects one's self-concept. Acceptance and adjustment mean learning how to best adapt to one's physical environment as well as developing a new self-concept, which may include difference values as to what it means to be worthwhile (Vargo, 1989).

In the area of self-esteem and self-concept, Schlieper (1985) indicated that the handicapped individual is more vulnerable than the nonhandicapped to a variety of psychosocial problems. One such problem is the enhancement of self-concept, while coping with the physical handicap or visible difference.

Self-concept may be influenced by whether a disability was present at birth or happened later to a previously nondisabled individual (Vash, 1981). It is considered by some that to be born with a handicapping condition is somehow less respectable than to have acquired a disability later on in life. Vash (1981) discusses the relationship between the stage of one's life when the disablement occurs and its influence on the reactions that will be experienced. This is partly because the disability affects the way one is perceived and treated by others, and partly because different developmental tasks are interrupted during different life stages. For instance, if individuals become disabled in infancy or childhood they may, like persons born with a disability, be subjected to isolation and separation from the mainstream in family life, play and education (Vash, 1981). The person who becomes disabled later in life may not have to face these issues, but will have to confront different ones, such as learning to adjust to doing daily tasks in a different manner, such as dressing oneself or not being able to perform a variety of physical activities, such as writing notes in a classroom.

Other variables which may influence the development of self-concept in the visibly different individual include the functions impaired and the severity, visibility and stability of the disability and pain. Regarding the functions impaired, and despite the commonalities across all types of disablement, it is obvious that losing eyesight, hearing or ability to move a limb will generate different reactions because each creates different problems. One such problem is the extent to which a disability interferes with physical attractiveness. Sensitivity to the lack or loss of personal attractiveness sometimes can exceed the pain felt about the more obvious functional impediments disability entails (Vash, 1981). Displeasure with one's looks may be increased by the reactions of others, which may lead to a lower self-concept, and may be especially difficult during adolescence as development of self-image reaches an especially critical stage in dealing with physical change. Social attitudes, particularly as they are reflected in the attitudes of family members, friends, teachers, classmates and others, strongly influence adolescents' self-images. Negative attitudes by any of these individuals can be detrimental to any person, but may be particularly painful for disabled teenagers who have not yet developed secure self-concepts. Although adolescence is a difficult time for any youngster, it is even more difficult for a teenager with a handicapping condition. Though there may be similarities between the difficulties of disabled and nondisabled teenagers, for the disabled adolescence many ordinary problems may be magnified, and frustrations and uncertainties tend to be more frequent and intense (Winter & DeSimone, 1983).

The severity of disability may also influence the development of self-concept. Varying degrees of severity create different kinds of situations for disabled people to respond to, independent of personal dynamics. For example, a young woman with a partially paralyzed leg will not experience the fear associated with the realization of total dependency on others which a quadriplegic may have to experience. Related to the severity of disability is the visibility of disability. For instance, a visible impairment such as having to use a wheelchair could be difficult interpersonally, because the individual has to cope with the possibility of being ignored by other people, not because of personal factors, but because of the wheelchair. The stability of the disability can also influence self-concept. A progressive disability can produce a negative outlook because the individual is under the constant threat of losing some ability to function, for example, a person with a neuro-muscular disability may no longer be able to use the arms due to a constant erosion of muscle strength. The variable of pain can also influence self-concept, as pain can influence both behaviors and feelings. For some people pain may lead to a lower self-concept, and may lead to decreased social activity, eroding the sense of self-worth.

There are no universal principles to simplify the task of learning to live with a visible difference. Success, to a large degree, depends on the physiological, psychological and emotional makeup of the visibly different person and the support and encouragement received from family, friends and others (Penn & Dudley, 1980). Within the educational system, especially in secondary and postsecondary schooling, limited work has been done in trying to help visibly different students cope with specific emotional difficulties arising from their handicaps. Within mainstreamed classrooms, school children with visible differences and their classmates are often instructed: "Say it all together. Don't be different. Behave right. Do it right. Be right." (Timberlake, 1985, p. 232). For students with visible differences, this indicates they are first expected to cope with themselves and their differences, and secondly to master academic learning tasks (Timberlake, 1985). Self-concepts of individuals with visible differences may suffer even more if they believe that they are academically delayed in comparison to classmates who do not have a visible difference.

Consulting with regular classroom teachers is an important aspect of promoting successful mainstream experiences for visibly different students. Preparation of teachers may be important not only in facilitating positive attitudes, but in facilitating an understanding of handicaps and their implications in the classroom (Dunn, McCartan & Fuqua, 1988). Also, research indicates that the attitudes of the nonhandicapped students toward the visibly different classmate is an important component to the success of mainstreaming (Dunn et al., 1988). Consultant service can assist both teacher and students by increasing the teacher's understanding of the faulty attitudes and beliefs that visibly different students maintain about academic performance and their possible resultant behaviors, and by helping the teacher to develop a classroom atmosphere that is supportive of all students. Increased teacher awareness of the needs of visibly different students and the development of a supportive classroom atmosphere are of primary importance in increasing the efficacy of any educational intervention (Bello, 1989). For instance, education about a variety of handicapping conditions can assist handicapped students in adjusting to their own handicap by letting them know they are not the only ones with a disability (Dunn et al., 1988).

Student ability to learn is determined largely by self-concept (Jones, 1985), the internalized self description used by an individual, based on the roles played and the attributes and beliefs held (Beane & Lipka, 1984). Self-concept accounts for a significant portion of achievement independent of measured intelligence, socioeconomic status, educational aspiration and the expectations of family, friends and teachers (Jones, 1985).

The Penn and Dudley (1980) study indicated that most handicapped students did not see their disability as a great tragedy, but as a fact of life, an inconvenience and a cause of frustration. On the other hand, Thomas, Bax and Smyth (1988) found that handicapped students were more likely to experience difficulties, including severe social difficulties.

Frequently, low self-esteem is reinforced over the years (Kashani, 1986). Only in recent years has there been an increasing awareness of the importance of personal characteristics in the ultimate success of handicapped individuals (Abramson, Ash & Nash, 1979). It is felt that without specific training designed to increase social acceptability, independent functioning, and better performance of everyday skills, many handicapped persons will never achieve self-sufficiency.

Education and Employment

Self-sufficiency for many individuals', whether handicapped or nonhandicapped, is achieving postsecondary career training, which then may provide a higher standard of living, personal status and satisfaction. Rosher and Howell (1978) found that disabled students appear to be extremely similar to nondisabled students in career goals, and that being physically disabled did not affect level of educational and career aspirations. On the other hand, one finding in Rosher and Howell's study (1978) was that the disabled scored lower than the nondisabled in terms of career aspirations in the professional realm, while the Canadian Health and Disability Survey reports that there are relatively few differences between the types of occupations held by disabled and nondisabled persons (Government of Canada, 1986). This then raises the question of why such a small number of physically handicapped individuals go on to a postsecondary institution such as a university or community college, as reported by the Canadian survey which also states that a high number of individuals who report having a disability have low levels of formal education. In Canada, forty-three percent of the disabled population have only eight or fewer years of education compared to seventeen percent of the nondisabled population. Fifteen percent of individuals with a disability have received some postsecondary education, compared to thirty-one percent of the nondisabled population. For those in school, disability has clearly had an important influence on their school career. The majority of the disabled population currently enrolled in school state that their education had been interrupted for long periods of time, while sixty-five percent took fewer courses, sixty-two percent at some time attended special classes and forty-six percent at some point had to change schools because of their condition (Government of Canada, 1986).

Another way in which visibly different individuals achieve self-sufficiency is through employment. One way that the differences can be lessened and equality increased is through employment, which can occur only if visibly different individuals are given an opportunity to work. Employer attitudes toward persons with disabilities have been considered one of the primary factors contributing to both unemployment and underemployment of disabled persons, though several studies describe the disabled as competent, reliable employees (Wilgosh & Skaret, 1987). Thomas and Thomas (1984) indicated that for some employers the handicap an individual has did not effect being offered a job, whereas other studies, such as the one conducted by Krefting and Brief in 1976 (cited in Thomas & Thomas, 1984) found that the number of job interviews for the handicapped were significantly lower, and they were given gloomier job market outlooks (Thomas & Thomas, 1984). It is felt that employers tend to focus on the limitations of the visibly different individual rather than on their capabilities (Wilgosh & Skaret, 1987).

This type of attitude not only leads to frustration for the visibly different person, but may also lead to apathy. Many visibly different adults develop a defeatist attitude of feeling that there is no reason to get training for employment, or even apply for a job, because the handicap will result in their being refused employment. Another difficulty for some visibly different adults in the province of Alberta is that they may lose access to medical benefits and, in Alberta, the Assured Income for the Severely Handicapped (A.I.S.H.).

Assured Income for the Severely Handicapped is a program for adult Albertans with severe and permanent handicaps. It is designed for people who have reached their full potential for training, rehabilitation or gainful employment and are substantially limited in their ability to earn a livelihood because of their medical condition. A.I.S.H. is not a pension program, as it attempts to incorporate incentive provisions. The program designed was thought to be fair and equitable to persons with disabilities and at the same time to address some of the concerns raised by professionals and advocates. Therefore the program requires that its recipients be severely and permanently disabled. Also, the legislation places very specific expectations on individuals with disabilities, such as the requirement that disabled persons must seek and accept reasonable employment for reasonable wages, retain employment that can reasonably be held, collect income to which they are entitled and participate in appropriate training or rehabilitative measures. It should be noted that a recipient of A.I.S.H. can earn only a specified amount without reduction of the A.I.S.H. payment. Once that amount is exceeded, and depending upon the level of earnings, deductions will be made from the A.I.S.H. benefit. For instance, a single person may earn up to one hundred and sixty-five dollars per month ($165.00), with no reduction in the A.I.S.H. benefit.

Within the A.I.S.H. regulations the term severe handicap is defined as a condition that, in the opinion of the director, with the advice of a physician, so severely impairs an individual that it substantially limits the ability to earn a livelihood and is likely to continue to affect that individual permanently because no remedial therapy that would materially lessen the impairment is available (Alberta Government, 1991). A.I.S.H. eligibility depends upon the impairment limiting the ability to earn a livelihood. It is the medical condition that must be the primary cause of the inability to earn a livelihood, not factors such as age, education, location and lack of jobs (Alberta Government, 1991). The judgement about whether the condition substantially limits the ability to earn a lifelihood is not entirely a medical decision, but also relies upon social work/rehabilitation judgement. A.I.S.H. regulations also stipulate that the individual cannot have refused to seek or accept reasonable employment for reasonable wages. Reasonable wages would be at least minimum wage or the training allowance provided in training or rehabilitation facilities. Persons receiving a training allowance or minimum wage would be required to continue the employment, but could be eligible for A.I.S.H. for additional income, if other eligibility criteria are met (Alberta Government, 1991).

The A.I.S.H. program finds the World Health Organization's definitions of impairment, disability and handicap to be helpful in distinguishing between these three concepts. An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function. For the purposes of A.I.S.H., existence of an impairment is not sufficient to establish eligibility. A disability is any restriction or lack of ability to perform an activity in a manner or within the range which is considered normal. A disability represents a departure from the norm in terms of performance of the whole individual, as opposed to performance of the organ or mechanism (Alberta Government, 1991). A handicap is a disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual. For the purposes of A.I.S.H., a judgement is required as to whether severely impaired individuals, within the context of their particular personal, social and environmental situations, have a handicap which limits employability (Alberta Government, 1991). The A.I.S.H. program requires that this subjective judgement be made based on the individuals' life situation, not merely on classification of medical conditions or other broad labels. For instance, an individual who has a neuro-muscular disability, with a university education who can work as a teacher has an impairment and a disability with respect to mobility, but is not handicapped in the ability to earn a livelihood.

A concern expressed by A.I.S.H. recipients is becoming employed, which precludes A.I.S.H. funding and, later, losing their employment because of their medical condition. It is important for A.I.S.H. clients to realize that handicapped persons who are medically qualified for A.I.S.H. but whose level of earned income disqualifies them from A.I.S.H. benefits may reapply if their earned income is reduced. If a file has been closed because the recipient has taken employment, and then they lose the employment due to a medical condition, within a period of twelve months, the file may be reopened by conducting a financial eligibility review and by updating the file. After the twelve month period the individual may reapply, and a full application is taken.

In 1982 there were over two million handicapped people in Canada (Obstacles, 1982), yet it is felt that a small percentage of these people are working in competitive employment, and many more are living at the poverty level, due to unemployment, partially through lack of job opportunities. The Canadian Health and Disability Survey reports that forty-one percent of the disabled adult population who are of working age (15-64) are employed, compared to sixty-seven percent of the remainder of the population. Also, the survey reports that fifty-two percent of the disabled adult population are not in the labor force, are not working and are not looking for work, possibly because of the disability (Government of Canada, 1986, p. 66). This in part may be due to only a small percentage of disabled adults going on to receive some form of postsecondary education, which has previously been discussed. Whether the disabled adult population has received some formal training or not, the survey reports that only six percent are unemployed and seeking work. An important factor which influences the disabled individual's likelihood of employment is severity of disability The Canadian Health and Disability Survey reports that the possibility of employment declines with increasing severity of disability. It therefore appears that the presence of a disability is a major contributing factor to the lower labor force participation rates among disabled persons. Of those disabled persons not in the labor force the survey reports that fifty-seven percent are completely prevented from working by their handicapping condition, and another twenty percent are limited to some extent by their health (Government of Canada, 1986).

This lack of participation by disabled adults in the labor force will directly affect their level of income. A comparison of income levels among disabled adults and the Canadian population in general indicates that thirty percent of income recipients in the total population have incomes of twenty thousand dollars ($20,000) or more, in comparison to fourteen percent of those with a disability (Government of Canada, 1986, p. 85). The survey reports that the level of income for those with a disability tends to decline as the severity of the disability increases. The survey also indicates that individuals with the most severe levels of disability are those least likely to earn an income, and are also more likely to have additional expenses as a result of their handicapping condition (Government of Canada, 1986).

Preparing for a vocation, seeking employment and retaining employment are three important tasks that must be satisfactorily accomplished by persons with disabilities if they are to be successful in their vocational and career development. The satisfactory completion of a vocational preparation program is an important step toward successful employment and career development for persons with disabilities. Social and self-presentation skills are important to the successful completion of such a program, and the lack of these skills may be a significant barrier to success in rehabilitation programs. An important phase of career development is job seeking. The ability to conduct oneself effectively in a job interview is seen as critical by several investigators, and the interview is probably the most important selection device used in making employment decisions. Employers use interviews to measure applicants' future work potential and frequently regard satisfactory interview behaviors as evidence of the ability to function independently in a work setting. Graduates of vocational rehabilitation programs have often been characterized as lacking the social and self-presentation skills critical to effective interview performance (Farley & Hinman, 1987). The need to complete training, conduct oneself well in a job interview, and relate to co-workers and supervisors effectively is well documented, as is the need for effective social and self-presentation skills. There is little documentation concerning the most effective interventions for successfully teaching these skills to persons with visible differences.

Physically disabled individuals who are mainstreamed into an able-bodied environment, such as a university, community college or the work place, must communicate particular needs and feelings to individuals who are unfamiliar with the experience of physical disability. Some professionals feel that it may be even more important for these disabled individuals than for the general population to learn appropriate assertive behavior (Starke, 1987). Morgan and Leung (1980) found that individuals given assertive training showed a significant difference in acceptance of disability when compared with individuals who experienced no assertiveness training. The few studies that have been conducted regarding assertion training with physically handicapped persons have found that such training appears to increase acceptance of disability, improve self-concept, enhance social interaction skills and increase assertive behavior of physically disabled individuals (Morgan & Leung, 1980; Grimes, 1980; Starke, 1987).

Social Competence

In order to grasp the complexity of personal adjustment for the individual with a visible difference, it is vital that the influence of attitudes toward disability be appreciated. External attitudes strongly influence the attitudes which individuals with visible differences may develop toward themselves on the basis of repeated social interactions. Negative social interactions may develop because of perceptions others have regarding the handicapped. Limited physical accessibility to public buildings may reflect social evaluation of the handicapped. While there have been laws enacted stating that all newly constructed buildings must have access for people who use wheelchairs, conditions remain less than ideal. For example, there may be an entrance that is accessible for someone who uses a wheelchair, but it may be in the back corner of the building, not through the front door where other members of the public may enter. This type of difference may have a negative impact socially on the handicapped, being separated in places that are supposed to be for all people, handicapped and nonhandicapped.

Richardson (1976) has suggested that a person with a visible difference needs a high level of social competence to overcome the social effects of the disability, yet much of the research done within this area indicates that many are deprived of the experiences necessary for the development of social competence and social skills (cited in Thomas et al., 1986). Research has indicated that a young person with a physical disability is likely to lack social independence, to become socially isolated and to experience difficulties in maintaining social relationships (Thomas et al., 1986). While both able-bodied and physically disabled young people experience difficulties in social situations, those with physical disabilities experience difficulties that are more severe in nature (Thomas et al., 1986). Clarke, Riach and Cheyne (cited in Thomas et al., 1988) found that social relationships of children with disabilities were frequently impaired. Disabled children were found to be less likely to communicate with other children, more likely to play alone, and more likely to engage in passive activities by listening to or watching others. Visible differences in children have also been associated with lower levels of self-confidence, greater self-depreciation, and difficulties in interpersonal relations. Physically disabled persons also face a social handicap in that nondisabled persons may tend to avoid social interaction with them (Mills, Belgrave & Boyer, 1984). One way persons with visible differences may overcome this secondary handicap is by being more assertive in social interactions. Evans (cited in Mills et al., 1984) stated that "Disabled persons should not accept a passive, submissive role but rather they should assume control of the social environment around them by creating a positive image and displaying behaviors that lead to positive, accepting attitudes on the part of the nondisabled population" (Mills et al., 1984, p. 2).

Persons with visible differences with the support and encouragement of family, friends and others can learn social assertiveness through social skills training. It is felt by some researchers that the extent of the social difficulties for people with disabilities is of sufficient magnitude to warrant intervention, yet structured programs of social skills training tailored specifically for their needs are not generally included as part of the education curriculum (Thomas et al., 1986). Some professionals who work with physically handicapped persons feel that social skills training programs should form an integral part of the program of independence training available for persons with physical disabilities.

Role of the Family

There is evidence to support the view that families with a child who is handicapped experience more stress than families with only nonhandicapped children (McDonald, Kysela & Reddon, 1986). Blacher (cited in McDonald et al., 1986) stated that the child with special needs may have a negative effect on the marital relationship, sibling relationships, and relationships with friends and other relatives. For instance, the disappointment which can be experienced by some parents, along with the unrealistic but at times common experience of guilt, seems sometimes to push the marital partners apart. Thoughts of blame and weakness, and the inability to give or accept comfort can isolate the parents from each other and may build barriers which become more painful as the years go by and these barriers may never be overcome (Goldenson, Dunham & Dunham, 1978). Despite the potential difficulties which may arise from having a physically handicapped person within the family, some families appear to adapt well without adverse effects on the well-being of the individual family members or on overall family functioning (McDonald et al., 1986).

Professionals working with visibly different persons on achieving independence should understand the vital role parents and siblings play in this process. The parents' emotional response and overt attitude toward their visibly different child is central to the child's emotional adjustment, ego development and social relations (Blumberg, 1975). Parents react in different ways. Some parents, after initial dismay and sorrow, may resolve to treat the child with loving nurture as much like a 'normal' child as is feasible and tends to seek the help of appropriate professionals. This accepting type of parent is also helpful to the siblings of the visibly different child, allowing the siblings to develop increased tolerance for differences as well as higher levels of empathy and altruism (Powell & Ogle, 1985). The manner in which a handicap is interpreted and accepted delineates its impact on the siblings involved. It is felt that a positive communication pattern between nonhandicapped siblings and parents of handicapped children is instrumental in achieving optimal sibling adjustment.

A second parental style is characterized by an overreaction with pity rather than empathy. These parents inhibit the handicapped child's development with overindulgence and overprotection. By shielding the child from the physical and personal world, this parenting style reduces the child's normal ego development and potential for social adjustment (Blumberg, 1975). Overprotective parents may lead to the siblings being overprotective as well, with the siblings become alternate caregivers, especially older female siblings. This increased responsibility may create problems for the siblings involved, who may become resentful of the 'parenting' role they have had thrust upon them and resent having less time to spend in their own social activities or the extra responsibilities around the home, such as dressing or feeding their handicapped sibling. One positive aspect which may arise from this is that if a child wants to participate in a social activity, the visibly different sibling may be included to allow the nonhandicapped child to avoid missing interaction with friends. Physically handicapped children who are included in an appropriate social environment are provided with role models of social interaction. The overindulgent parenting style also may lead to siblings of a handicapped child becoming resentful, when all wishes of the physically disabled child are met, while the nonhandicapped child may be ignored There may be resentment of the extra responsibilties caused by the handicapped child being given no duties for self or home care. Whether the parents are overprotective or overindulgent, the extra responsibilities given to the nonhandicapped siblings may be balanced by an increase in attention given the nonhandicapped child and the sincerely expressed appreciation of the parents for the assistance given by the child (Powell & Ogle, 1985).

Another example of parental anxiety or overprotection is seeking to compensate for the visible difference. Parents may be determined that their visibly different child will be the 'best' within the area of the handicap, for instance, their child will be the most capable cerebral palsied child who ever lived. These well intentioned parents at times overstimulate or overchallenge their child, and in extreme cases, the demands they place on the child may cause the child to withdraw, as a response to the unbearable pressure (Goldenson et al., 1978).

A third type of parental style results from parents being overwhelmed by guilt for producing a defective child. This guilt may be projected in the form of hatred and rejection of the child, or in the form of overprotection and overindulgence. The feelings projected by the parents may be mirrored by the nonhandicapped siblings, who begin to act and react in the same manner as the parents. Guilt ridden parents may teach the nonhandicapped siblings to feel fearful and anxious about how to interact with their handicapped sibling (Powell & Ogle, 1985). Nonhandicapped siblings also may feel guilty because of their own good health.

The parenting style affects how visibly different individuals accept their disabilities, and their achievement later in life. Siblings also play a role in the development of emotional stability. The brothers and sisters of persons with handicaps are vital components in the family system, influencing the handicapped individual through their interactions and are, at the same time, influenced by their handicapped brother or sister (Powell & Ogle, 1985).

Coping Techniques

McCubbin and McCubbin (cited in McDonald et al., 1988) have provided a model of family adaptation which may enhance professional understanding of the way in which families function with the stressors inherent in raising a handicapped child, the T-Double ABCX Model of Family Adjustment and Adaptation, which aims to provide a model which will not only be able to predict the degree of disruption in functioning that a family is likely to experience in the event of a particular stressor or change in the family system, but also the level of family ability to adapt and achieve a new balance in functioning after a major disruption or crisis occurs (McDonald et al., 1988). It is important for professionals to realize that for families the birth of a handicapped child may create a crisis situation that will never by resolved and continuous adaptations on the part of family members may be necessary.

Adaptations on the part of family members and the visibly different individual may manifest themselves through a variety of coping mechanisms or stages of acceptance. The initial reaction has been described as one of disbelief and denial (Blumberg, 1975). Parents may react with the thought that the doctor is mistaken, the disability will pass. The second stage of reaction is that of frustration and anger that the disability has actually occurred. This may be followed by a reactive depression as both the parents and the physically handicapped individual realize and sometimes exaggerate the influence the disability will have on their lives. This realization about one's own difference may come later in life for the handicapped individual, as a young child does not have the mental or emotional capacity to comprehend all of the relevant aspects of the disability. The final stage is that of acceptance, realizing and accepting the impact the disability will have on their lives, which will allow realistic planning for the future.

A visibly different child may cope in several ways. A child may attempt to deny the physical difference, which may be done in various ways, similar to the ways in which most children fantasize, but becoming more important to the child with the onset of understanding personal difference. The child may engage in make-believe fantasies, or in wishful thinking about a magical cure, perhaps through a new medical discovery, or may simply deny the existence of a physical difference. This involves ignoring reality and behaving as if there were no difference between one self and others (Timberlake, 1985).

Besides behaving as if there were no differences, a visibly different child may seek symbolic repair of the different self in a variety of ways. Through acquisition and substitution, a child may symbolize extension or disguise of a body part, a new wholeness, or a compensatory power and strength. Secondly, the child may identify and incorporate selected attributes or behavioral styles of fictional characters, famous persons or helping professionals, which then may evoke a sense of renewed or repaired self. A third method a visibly different child may use is that of compensation. By emphasizing the competent self, this defense supports accomplishment in areas not influenced by the difference, which brings a sense of recognition and success, while minimizing the sense of damage and failure. A fourth method is that of reaction formation, with symbolic repair occurring through high achievement directly in an area closely associated with the difference, or indirectly in a selected area of compensation (Timberlake, 1985). Examples of reaction formation include an individual with a deformed hand becoming adept in dancing, or someone who cannot physically withstand the rigors of full time employment working part time. It should be noted that these methods of coping may be reasonable and healthy, or carried to inappropriate and dysfunctional extremes.

Integration has been defined as the equal and orderly cooperation of different parts which are in relation to each other so that a unity of independence of action can be reached (Cornelissen & McDougall, 1985). For individuals with visible differences this means that they must first integrate their handicapping condition with themselves. To integrate means to live with the difference, not just to accept it. Next the visibly different person needs to integrate into the home environment, which can be family, friends, neighbors and the people with whom they live. The final level of integration occurs when the visibly different person becomes an active participant in the community. These levels of integration are a continuing process, as one is always attempting to become integrated in a variety of settings.

Cornelissen and McDougall (1985) state that when visibly different individuals say that they can not do a task because they are handicapped this statement can be seen in two ways, either positively or negatively. Positively, this statement can mean that "I cannot do several things in the normal way because a part of my body is not able to make the desired movements" (Cornelissen & McDougall, 1985, p. 183). Negatively, this statement says "I do not like to do that or I do not like to find ways for substitution and my alibi is my handicap" (Cornelissen & McDougall, 1985, p. 183). The positive viewpoint looks at the possibilities and impossibilities in a realistic manner, and allows for a readiness to consider them. The negative side makes it all right not to do things of which they may be capable, and does not allow them to discover their potentials. Cornelissen and McDougall (1985) believe that many visibly different persons use the negative viewpoint, perhaps without realizing that they are doing so. It is felt that the viewpoint that they hold is not completely only theirs, as there is 'nonhandicapped' support of this negative outlook (Cornelissen & McDougall, 1985).

Besides developing an attitude which is either positive or negative regarding the handicapping condition a visibly different person must also develop an attitude regarding a viable role as a human being. When one says that 'I am human', positively this means "I want to be treated as a person with my own possibilities, impossibilities, and dependencies. I want to be heard and to be addressed" (Cornelissen & McDougall, 1985, p. 183-184). Negatively, this can mean "I want to be heard but I want you to see how pitiful I am. Speak to me but do not expect too much from me because I am handicapped" (Cornelissen & McDougall, 1985, p. 184). The positive viewpoint allows for the individual to be an active participant in everyday life, whereas the negative outlook would allow the person to be human but to be inactive in everyday life. It is believed that when visibly different persons try to integrate their handicapping condition with their humanity, these individuals can learn to live with their handicap, and not be frightened to be a handicapped human (Cornelissen & McDougall, 1985). Visibly different individuals who hold the negative viewpoint make the discrepancy between being handicapped and being human greater and greater. These individuals need to learn that their handicap is a fact, and that there is more to them as a person than just their handicapping condition. Vargo (1986) believes that a physical disability causes the individual to consider many questions that nondisabled people do not need to consider until later in life, for instance, personal mortality and the relevance of physique and physical beauty to self-concept in relation to being worthwhile as a human being.

Acceptance of disability evolves gradually for most visibly different individuals, over a span of years which have been filled with instructive experiences (Vash, 1981). The process of living teaches individuals little by little that disablement need not be viewed as an insurmountable tragedy. Self-dependence, even a small amount, helps visibly different individuals preserve their sense of dignity and self-worth, whereas dependence tends to deprive them of initiative, self-esteem and hope for the future. What disabled persons learn to do for themselves is more important than what others can do for them (Goldenson et al., 1978). As the struggles to survive, work, love and play show evidence of some success, visibly different persons may find awareness of disablement slipping farther into the background (Vash, 1981). It is thought that psychological adjustment to disability is "primarily a function of one's philosophy of life. It both determines, and is a reflection of, how one views what it means to be a person with a disability in terms of abilities, roles and expectations" (Vargo, 1989, p. 13).

Nancy Kerr (cited in Vash, 1981) describes five major stages in the process of adjusting to permanent disability: shock, expectancy of recovery, mourning, defense and adjustment. These stages are points on a continuum, not discrete categories, and they describe common behavioral phases. Within the shock stage, individuals have not fully comprehended that they are disabled, and little anxiety is present. The realization that there is something wrong is often accompanied by expectancy of recovery. In this stage there is no motivation to learn to live with the disability, because it is believed it will go away. With realization that the handicapping condition is permanent, mourning for the loss may follow. In this stage, acute distress, readiness to give up and thoughts of suicide are common. Some individuals may remain in this stage indefinitely, resigning themselves to their fates, while others may move on to the defense stage, which is characterized by coping efforts and interest in learning to be as normal as possible. A healthy defense is when the person acknowledges barriers, and then either conquers or circumvents them. A neurotic defense stage is when the person uses defense mechanisms which deny that barriers exist. People who reach the final stage, adjustment, no longer consider their disability as a barrier to be fought, but find ways to satisfy their needs, allowing the feeling of competence (Vash, 1981).

Perceiving a person with a disability as coping with the problems at hand, or as succumbing to them, has contrasting effects on how well adjusted that person appears.

When people with visible differences are perceived as attempting to utilize their assets and improve their lives, they are regarded as determined or courageous. On the other hand, when the person is preoccupied with the undermining aspects of the situation, they may be seen as less worthy (Wright, 1983).

Individuals who cope with their visible differences take an active role in shaping their own lives, and see their physical limitations as being manageable, while individuals who succumb to their visible differences place a strong emphasis on what they can not do, believe themselves to be passive victims of fate, and view their physical limitations as the dominant factor in their life (Vargo, 1988). A difference in values is the main distinction between coping or succumbing.

Wright (cited in Vargo, 1988) states that persons who live according to the coping framework probably have changed their values along four dimensions. First of all, the individual has enlarged the scope of values, putting behind them the preoccupation with the loss of certain physical limitations and replacing this with an emotional appreciation of values which go beyond the loss. Secondly, people who cope well tend to view intrinsic values in life as being more important than physique. Third, persons who cope are able to contain the effects of the disability to the areas of functional limitation that are truly affected. These individuals usually view physical ability as a way for carrying out specific tasks. Finally, individuals who use the coping framework tend to view life more in terms of asset values than comparative values. Comparative values are judged in terms of a comparison with performance of other people in relation to that activity, whereas asset values refer to the intrinsic value of an activity (Vargo, 1988).

A main factor within the coping and succumbing focus is the personal belief of problem ownership, and whether the insider or the outsider has the problem. Insiders are the individuals who experience or evaluate their own behaviors, feelings or problems. The outsider is the person observing or evaluating someone else's behavior. In the coping - succumbing framework the insider, the person, not only wishes for improvement but is faced with the necessity of coping with the difficulties. In contrast, the need to cope with disability problems may not be felt by an outsider, such as a stranger, friend or professional working with individuals who have visible differences (Wright, 1983).

At times physically disabled individuals may need counselling to help them learn to cope with their visible difference. Systematic counselling can result in visibly different persons believing that being handicapped does not mean that they are incapable or inferior (Bello, 1989). The problem with mainstream counselling approaches, for disabled people, is that they often are inaccessible in several ways. First of all, they may exist in settings which are architectually inaccessible. Secondly, they exist in the mainstream, and if the prospective client has been placed in a 'special' segregated track, they may not have access to mainstream facilities (Vash, 1981). Third, when people are, or become, disabled, professionals tend to refer them to rehabilitation agencies, without considering other resources. Finally, professionals in mainstream settings imagine they can not work with people with visible differences because they are not rehabilitation experts. It is felt that a counsellor should have a "rudimentary knowledge of the behavioral manifestations of the medical condition, and be skillful at implementing counselling strategies which are compatible with the intra and interpersonal dynamics (Vargo, 1978, p. 14). Counsellors should have some understanding of the medical condition involved when dealing with somebody with a physical disability. The major goal of counselling should be seen as helping the person with a visible difference acquire the skills necessary to fulfill the responsibility of achieving societal acceptance (Vargo, 1978). Consequently, mainstream counsellors only need to be prepared to take a disability in stride and not let it become an artificial focus in their counselling efforts (Vash, 1981).

There are a variety of methods a counsellor can use to help the visibly different person 'accept' the disability. One strategy is to provide descriptive feedback to the physically handicapped person. Feedback described in behavioral terms can help modify self-concept. For example, many people, whether they are disabled or not, have difficulty describing their strengths. Therefore, an important role of the counsellor is to identify strengths and abilities to their clients which the clients may not see themselves (Vargo, 1978). Another strategy is a cognitive approach which enables a physically handicapped person to first evaluate the nature and difficulty level of a task before attempting it, second, to formulate a plan of action, and finally, to explore possible options (Bello, 1989). If visibly different persons can apply the appropriate strategy to the situation at hand, their chances for success will increase. A counsellor should help persons with visible differences realize that success is determined by self-improvement rather than by comparisons with other individuals and that they are responsible for their performance on any given task (Bello, 1989). The counsellor needs to assist the visibly different person in realizing that the physical difference need not be the most important concern in life and that people can be different and equal (Vargo, 1978).

Systems theory, a recent major theoretical alternative, may be useful in the counselling of visibly different persons. Although new, it builds on the important past work of other theories. The systems view is one in which the interaction between and among individuals, families and environments is thought to be the central fact of being in the world. This theoretical framework not only works toward individual change, but also works toward changing the transactions of the individual with the environment, and may even attempt environmental change itself (Ivey, Ivey, & Simek-Downing, 1987). In adapting to their environments, systems will attempt to cope with external forces by ingesting them, acquiring control over them or some combination of these processes. It is important to realize that no system can be understood without studying the forces that interact upon it and the changes to the system from these interactions (Katz & Kahn, 1967).

Within general systems theory there are two types of systems, open and closed. The organism itself is an open system. A system is thought to be closed if no material enters or leaves it, and open if there is import and export of material (Bertalanffy, 1968). In systems there are roles, norms and values. Systems comprise "the role behaviors of members, the norms prescribing and sanctioning these behaviors and the values in which the norms are embedded" (Katz & Kahn, 1968, p. 37). Roles describe specific forms of behavior associated with given tasks and develop originally from task requirements. Norms are the general expectations for all roles in a system or subsystem. Values are "the more generalized ideological justifications and aspirations" (Katz & Kahn, 1968, p. 37).

Another aspect of systems theory is transactional analysis, a humanistic derivative of psychodynamic theory. Although it is not usually thought of as a systems theory the word transaction fits systems concepts. In transactional analysis the goal is to change the transactions individuals have with one another (Ivey et al., 1987). James and Jongeward (1971) summarize transactional analysis as being "a rational approach to understanding behavior - based on the assumption that all individuals can learn to trust themselves, think for themselves, make their own decisions and express their feeling. Its principles can be applied on the job, in the home, in the classroom, in the neighborhood - wherever people deal with people" (cited in Ivey et al., 1987, p. 338). There are four transactions people use when dealing with the environment. The first one is 'I'm O.K. - You're O.K.', whereby individuals believe that they are validated in the world, can form self-concepts, are acknowledged as individuals, and have positive self-identities as well as positive images of those around. The second transaction is 'I'm O.K. - You're not O.K.', persons believe that they are validated individuals who have positive self-images but believe that the world and others surrounding them are enemies and are threatening to their existence. The third one is 'I'm not O.K. - You're O.K.' In this transaction persons take upon themsevles the blame for things going wrong, are the recipients of negative parental (and other) messages, and are inundated with guilt. The individuals believe themselves to be bad and unworthy of positive feedback from important adults, family members and others. The final transaction is 'I'm not O.K. - You're not O.K.'. In this transaction, the individual has a poor self-image and hostile and angry feelings about others and the surrounding world.

This person has received the message of not being worthy of positive praise and dislikes those who withhold attention and positive reinforcement (Ivey et al., 1987).

With this theoretical framework the role of the therapist or counsellor is to target either individual, family or organizational change as the goal. This change can be achieved either through remedial therapy or counselling, or through a psychoeducational method, which involves the teaching of skills to prevent problems from occurring. Skill training, relaxation training and assertiveness training are methods which are typical of the psychoeducational approach (Ivey et al., 1987).

While generally applied to organizations, systems theory can be adapted readily to a variety of social groupings and settings. The concept of open systems which change both from internal and external interactions is useful in providing a framework for discussing the perceptions of the respondents in this study.

CHAPTER III

DEFINITIONS AND RESEARCH QUESTIONS

The following section discusses terms used in this study.

Definitions

Visible Difference -	A physical impairment which is visible.
Medical Conditions -	Although some specific handicapping conditions will be mentioned, descriptions of these medical conditions will be used in the discussion by describing the disability as degenerative or not, onset and the amount of deterioration, if any.
Coping -	The specific behavioral or cognitive actions that are used in order to respond to a problem.
-	The result of the action, such as coping appropriately or coping inappropriately.
-	"Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person". (Tunks & Bellissimo, 1988, p. 172).
Glenrose School Hospital -	Rehabilitation setting in Edmonton Alberta, which provides schooling to school-aged children, and provides other medical services to both children and adults in Northern Alberta.
Physio Therapy -	A branch of rehabilitation medicine which works with disabled individuals on an exercise program in order to develop and maintain maximum muscle strength and mobility to keep patients as active as possible.

-	Adapts and fits equipment, such as canes and back braces.
Occupational Therapy -	A branch of rehabilitation medicine which assists the disabled individual in developing skills to enhance independent living. For instance, the therapist can teach cooking skill adaptations to a person who uses a wheelchair.
-	Adapts and makes equipment which will aid the disabled individual in daily life, such as making a tray to fit on a wheelchair so the individual could write notes while attending classes.
Social Services -	Within the lives of handicapped persons, social services has a role in a variety of areas.
Home Care -	Provides equipment and services which will help the handicapped individual live a more independent life.
-	Home care can provide personal care attendants to help with personal care and home making.
-	Home care also provides equipment such as wheelchair cushions and bath tub aid.
ADL -	Aids to Daily Living
-	Aids necessary for daily life, such as wheelchairs, cushions and catheters, are provided to the handicapped person through ADL.
-	Amount of aid provided through ADL is a set amount and anything above that is paid by the individual.
Social Workers -	There can be different social workers in the life of handicapped persons.

- Social workers in the areas of home care, ADL and A.I.S.H. monitor the provision of services and equipment to persons who require them.

A.I.S.H. - Assured Income for the Severely Handicapped.

- Income which is provided to handicapped persons who are severely limited in earning a living.
- A.I.S.H. is discussed in detail on pages twelve through fourteen.

D.A.T.S. - Disabled Adult Transportaiton System which provides door-to-door service to individual with limited access to public transportation.

Research Questions

The following are research questions to be considered in the analysis of data. The questions have arisen from the literature surveyed in this area.

Question #1 - What is the role of the family?

This question deals specifically with the family system, and the role the system has played in the development and integration of the handicapped person. Consideration is given to the expectations parents, siblings and other relatives have for the handicapped person, and how these expectations effected the disabled person's development.

Question #2 - What is the role of the education system?

With regard to the educational system consideration is given to the accessibility of both schools and school programs, and how each of these has effected the schooling and school programs, and how each of these has effected the schooling of the handicapped person. The degree of accessibility can be expected to effect the integration and participation of the handicapped person. Other considerations include treatment of handicapped students by teachers in terms of integration and academic expectations.

Question #3 - What is the role of medical and related services?

With regard to the medical and related services system it is important to understand the role these individuals have in the life of the visibly different person, and informants' perceptions of how they have enhanced the process of integration, including the dissemination of information to other systems, which might help in the integration process. The effects of lengthy hospitalizations is explored.

Question #4 - What is the role of the employment system?

With respect to the employment system questions regarding accessibility arise, including access to the necessary training for the preferred employment opportunity, as well as access to the employment setting. Acceptance by employers and co-workers and the general satisfaction of the job will be considered.

Question #5 - What is the role of the social system?

The role of the social system is explored by examining the perceived acceptance of informants by their social groups. It is expected that this will change over time, and questions regarding these changes have been included in the interview schedule.

Question #6 - How does the individual system change over time?

This complex area includes the physical characteristics, interaction with the other systems and resulting modifications from these interactions. Topics discussed include perceived acceptance levels over time, the development of coping techniques, perceived achievement of normalcy and whether the handicapped person copes with the visible difference, or succumbs.

CHAPTER IV

METHODOLOGY

Literature in the area of self-reported experiences of visibly different individuals is limited. Some areas which have been explored are self-concept, career goals, integrative socialization including assertiveness training, support of family and professionals including educators and counsellors working with the individuals, some individual coping skills and employability.

This study was designed to investigate the perceptions of visibly different persons of their experiences from childhood to adulthood, in an attempt to gain insight into the areas included in the research questions. Questions to the informants were open ended to allow respondents to discuss freely their individual experiences, including the frustrations they encountered over the years, as well as their experiences in the family, in educational and hospital settings, in social settings and in places of employment.

The Informants

Rehabilitation and Special Education literature offers little on the perceptions of persons who receive services for living with a handicapping condition. This study attempted to explore individual perceptions of experiences, including coping with disability. The participants in this study were seven young adults, in their twenties to forties, who have a visible difference, such as assisted mobility, muscular problems including spasms and unusual speech. The individuals in this study have had a disability either since birth or with onset before or during adolescence. It was felt subjects who had acquired visible differences later in life would detract from the study as too many variables would need to be considered, lessening the focus of the main variable in the study, that of the experiences of persons with visible disabilities through childhood to maturity.

Instrument

As a suitable instrument could not be located, a guided interview schedule was developed to examine perceived changes in experiences and coping skills in childhood, adolescence and adult life, and useful personal and institutional interventions. The schedule was developed with the assistance of a researcher experienced in developing interview schedules. One change in wording was suggested by the Ethics Committee of the Department of Educational Psychology and this change was included in the schedule. Finally, the first informant selected was an unusually appropriate person to give constructive criticism, being both outspoken and accustomed to interviewing in her own professional career. Two concerns were the clarity of the questions asked and the possibility that some questions might be considered offensive by the informants, and this was of concern throughout all interviews. The first informant reported no difficulty with the schedule and no further changes were made. In subsequent interviews, where informants were uncertain about questions, further explanation was given by the researcher. No informants either appeared uncomfortable or indicated in any way that any parts of the schedule were offensive to them. Specific areas examined were the roles of professional agencies working with the family and/or the interviewee, including school, medical and other related personnel. Other areas examined were the family, social groups and employment related groups.

A copy of the instrument is found in Appendix B.

Procedure

The informants for this study were located through acquaintances of the researcher, who, like herself, have a visible difference. The researcher first explained the purpose of the study to the prospective informants. Once the informants agreed to participate in the study, the researcher then set up a time for the interview that was mutually suitable. When the informant arrived for the interview, the researcher gave the subject a copy of the interview schedule, allowing time to read through the questions which were to be asked. The researcher explained to the informant that if any questions were offensive or too personal there was no need to answer, and the interview could be terminated by the informant at any time. The informant was then asked if there were any questions. When any questions were answered, each informant signed a consent form, agreeing to participate in the study and allowing the interview to be tape recorded for accuracy of information, with the assurance that only the researcher would listen to the tape recording, only a handwritten transcript of the interview would be given to other individuals and no identifying information would be included in the final study.

Each subject was interviewed for about one-and-a-half to two hours, depending upon physical condition and language skills. Only one interview was not tape recorded, as the subject has a severe speech impediment, so the responses were written down by the interviewer.

The tape recorded interviews were analyzed in terms of commonalities of experiences and these were examined with the experienced researcher, to guard against personal biases of the researcher. The common themes were then clustered, for example, what interventions were seen by the informants as helpful in social integration. The analysis of data looked at each of the previously mentioned areas and the reported experiences in the visibly different individuals' lives at different stages. In this exploratory study, it was hoped that certain commonalities of experience would emerge to assist in the understanding of effective service provision for persons living with a handicapping condition.

Limitations

The major limitation of the study is the small number of informants and the way in which they were selected. There is no reason to believe that the informants represent the adult visibly disabled population in general. Another limitation concerns the interview and data analysis. At times there could have been experimenter bias as the investigator herself has a visible difference and uses a wheelchair. The visible difference of the researcher may have been a strength as well, in that the informants may have felt more comfortable talking to someone who has had similar experiences and who has an understanding of what it is like to have a visible difference. To guard against the investigator inadvertently over emphasizing responses that she felt personally relevant a co-investigator, who is not categorized as visibly different, assisted in analyzing transcribed tape recorded data.

Another limitation of this study is with the subjects used. Six of the seven subjects in the study were female, which introduces a gender bias towards the female perspective of living with a visible difference. Also, there is a possible limitation with the ages of the subjects. While the age range of the subjects in this study is from the early twenties to late forties, four of the subjects' ages were within the early twenties age range, while three were from thirty-nine to forty-nine. There were no subjects in the age range of the late twenties through thirties. It may be necessary to have information gathered from this age range, as a person in the early twenties may not accept or adjust to the visible difference, but by the forties may have accepted and adjusted to physical limitations. It was possible that the late twenties and thirties are important adjustment periods. In this study, due to the limited number of subjects, this possibility cannot be explored.

This study was designed to examine procedures used by the school system, teachers, counsellors and others. Interventions include coping with visible differences, by the affected students, classmates, families, employers and others. This study also investigated some of the interventions and adaptations within these persons' lives which have assisted them in achieving a higher level of education, social integration and employability.

CHAPTER V

ANALYSIS OF DATA

The information gathered for the purpose of this study was through self-reported guided interviews. The information received was then analyzed using a Systems Theory framework. The information the informants gave was compiled into a case study, which looked at six systems, individual, family, school, medical and related services, employment and social group systems.

Case Studies

Case Study #1

This forty-eight year old female has spinal cord paraplegia and is paralyzed from the waist down. Her paralysis resulted from an unfortunate medical mishap when she was approximately sixteen years old, which occurred when she underwent minor surgery connected with the disability she was born with, a mild form of spina bifida. She considers herself to be different from others. This feeling was very prominent during the initial years after her paralysis - "I wished things could be better, and it took me those years, till my middle twenties, to realize that they're probably not gonna be any better, any different, this is your body and this is the way its gonna be so just get on with it". The prognosis is unknown - "my longevity, it's really an unknown, and I just feel that everyday is a blessing". She believes herself to be an integrated member of society - "very much so". She perceives that she herself is responsible for her successful integration.

Family System

This informant grew up in a small town, and moved to the city in her early twenties. She has on sister whom she did not discuss in the interview except to say that she came from a two sibling family. She reports that both her parents were well educated people. She thought that her father believed her capable of achieving success despite her physical limitations - "my father always felt and believed that -- didn't know what I would be able to do but he always had that underlying belief that things would work its way out and there would be something that I would fit in to and that I would be happy doing and quite capable of doing". She feels that her mother experienced conflict - "her intelligent being as a teacher and an intelligent person was always in conflict with her mothering and her heart". She felt that a part of her mother wanted her to come home so that she could be taken care of for the rest of her life, whereas the other part realized that her daughter needed "to fall down and literally pick herself up". Overall she perceives that her family's reactions were helpful - "they endeavored to treat me just as the oldest child of a two sibling family".

School System

Schooling was disrupted during the high school years due to medical deterioration - "I lost a whole year and then because I had to have all this extensive plumbing surgery my high school years were really botched up". At this time the school system did not have semesters and she believes that with a semester system her schooling would not have been so disjointed - "because you didn't have semesters, if you missed, you missed a whole year". Because of her problems with school and with her medical condition she does not have happy memories of high school - "because of all my medical challenges and having so many hospitalizations".

Within the school system she felt that her teachers, classmates and friends were helpful with her integration into society after her accident - "I also think there was a sense upon my peers, my classmates and my teachers to try their best, and I also think they felt they had a role to play to try and help facilitate things -- in retrospect, I can see that". The principal was an amputee, with only one arm. She indirectly considered him to be a role model of how to enjoy life despite a disability - "a single armed person who was a curler and a golfer -- I mean it was nothing different -- it just was a norm". Also, she considered her own father to be "very, very helpful". As she missed quite a bit of school because of her medical problems, her father, also a teacher, "did a lot of student tutoring on the evenings, holidays, that sort of thing, I was very close to my father as a result of that".

Throughout her school career, even after the accident, she has felt accepted by her teachers - "they just treated me as another student in the classroom, they still had expectations that I would - have my homework even though I had all these other problems to deal with". She also felt that her teachers challenged her to her fullest potential, still being aware that her medical problems might cause her difficulties in school - "my teachers were very aware that my school load was at times more that I could deal with". She indicated that her classmates still accepted her after her accident - "I felt a very much a part of my high school group, I guess the only part that I didn't feel a part of was the whole sort of socialization, adolescent teen stuff". She felt accepted in the areas in which she felt she could make a contribution, such as the Students' Union. She continued her education, first going to college, and then later to train in a profession.

Medical and Related Services System

This individual was born with a mild form of spina bifida. She recalls having medical problems from grade seven on - "most of my summers I would have some sort of medical attention". Overall she feels that her hospitalizations have not greatly affected her.

In discussing medical personnel she believes that they did not always treat her with respect. After her medical mishap she did not receive straightforward answers as to why she had become paralyzed - "they just sort of said, well it's like a drunk up at the bar who's been at the bar too long and his elbow's gone to sleep, you've basically gone to sleep from the waist down". She felt that doctors could have "given me a better answer than comparing me to a drunk". With respect to nurses she feels that they also could have treated her better. She recalls hating her interactions with physio and occupational therapists - "they treated me like a kid". Overall, she did not see these therapies as useful.

Her interactions with psychologists were within the hospital setting after she became paralyzed. She recalls demonstrating her frustrations with regard to her paralysis one time - "after being put down in the children's ward and - I remember taking my brace off one night and throwing it at the door, and the next day or two I had a social worker, psychologist". She felt that "they wouldn't allow you to be frustrated".

Employment System

She worked for about seven years in the secretarial field and then worked in a profession for twenty years, and is satisfied with the jobs she has had. Because of declining health she is now retired.

She feels that her employers have been very good. When she began her career in her profession, she thought she had some proving to do - "especially during my initial years". She informed supervisors early in her career that she needed no exceptions made for her - "they thought maybe they would have to specialize my case loads and all that stuff, and I just said no, I've got my crutches, I'm able to get upstairs". She feels that her clients generally accepted her along with her disability.

Social Group System

She feels accepted by her social group and reports that this group "is not just disabled, I have probably more able bodied networking -- it doesn't mean to say I won't associate with disabled people". She thinks that she is "a very social person and therefore my needs are very socially oriented". She also thinks she is a fairly likeable person - "I like to think that I get along with people and I'm well liked by my peers".

Achievements and Future Goals

The informant realizes her prognosis and longevity are unknown and says that "every day is a blessing", dealing with life on a day to day basis.

Summary

In terms of coping with her disability, especially since her medical mishap, she believes that "attitude is first and foremost" and feels she is a very positive person. How the individual deals with the disability is very important to her and she feels that she taught herself how to cope with her disability - "once I started -- and it was a conscious decision on my part, nothing is going to change about my disability, about my body and about some of these things about my body I don't like, so I better just accept the realities and get on with my life".

She and her husband, who also uses a wheelchair, believe that initially it is up to them to make people feel at ease with their physical conditions - "helping to bridge that initial contact, to help make people feel at ease with the physical stuff". Once they have done that, and if people are still uncomfortable, they feel it is no longer their problem - "I just feel, you can't deal with me, then you've got the problem". She believes that "she cannot be responsible for how you feel or how you perceive things, same as you can't be responsible for how I feel".

Coping Techniques

This informant perceives that her coping skills in living with her disability have changed over the years - "definitely". She acquired her disability when she was sixteen years old and says, "when I was sixteen to twenty-one things were very poor on my part because I had a very rotten stinking attitude -- I guess once my attitude changed -- if I do the right seeding the seed sort of thing, keep up my end of it and try and lead my life as best as I can, I firmly believe you reap what you sow".

In her childhood there seemed to be two individuals who helped in the development of her coping techniques, the father who believed her capable of achieving, and a disabled principal as a role model of what can be achieved. In adolescence she coped by being angry at the medical profession and her own physical limitations. At times this anger was shown through aggression, such as throwing her leg brace against a wall. She saw her teachers and classmates as facilitators in helping her cope. She also coped by participating in extracurricular activities in high school. In adulthood, the middle twenties, she coped by accepting her physical limitations. She began to become a positive person, which she perceives helped her develop a strong sense of self-sufficiency. She strongly believes that she helped herself cope, and become integrated as a member of society - "it was a conscious decision on my part -- once I made the decision to get on with my life, despite these limitations, then my relationships started to blossom and I started to have fun in life".

Case Study #2

The informant is a twenty-four year old female with dystonia musculoram deformans, commonly known as general dystonia, a disability characterized by tight muscles, affecting the entire body - "the muscles do what they want you to do, not what you want to do". As little is known about dystonia, she is not certain as to whether the disability will plateau at a certain stage - "it's gone up and down, there have been times when I could do really nothing for myself and other good times when I've walked". Her disability was first diagnosed when she was seven years old. She perceives herself to be different from others and began to feel this in junior high school, when she lost her self-confidence - "I think up until I started feeling different, I did have confidence". She believes that she is an integrated member of society - "I can make a difference just like anyone else - you can make a difference".

Family System

She has lived in the city all of her life and her family system is made up of her parents, one brother and one sister. She reports that her brother does not have any problems with her disability - "he's a really good friend". On the other hand, she feels that "my sister is the other extreme, she's never thought of me as a friend, it's always, oh, I'm the younger sister". She believes that her sister has never really understood her or her disability - "although I'd never want her sympathy or anything, she'd never, you know, acknowledge what I've gone through and what I still go through". The informant states that her mother has helped her accept her disability - "my mom has just always been the one with me, oh don't give up, keep trying, do this, do that". She feels that her mother has coped very well, despite difficult times. She reports that her mother once told her that after struggling to get her daughter ready for school and then on her way, she would sit down and cry for an hour. She believes that her disability has been a source of frustration for her father, "even to this day". Through the years she believes that her disability has caused some problems between her parents - "my mom would say do that yourself - my dad would just want to come and do if for me even if he knew it was wrong". She states that her parents have always tried to keep their frustrations and disappointments from her - "they've always been very upbeat with me".

She does not feel that other relatives have helped her to become integrated. She feels that "they don't think of me in any grown-up way -- other relatives they treat me kind of young and it's just something you have to go along with".

School System

Elementary schooling included integrated and segregated school settings. For grades one and two she went to an integrated public school, and it was during that time her disability became apparent. By the time she was ready to begin grade three, her dystonia had developed to such an extent that she needed daily physio therapy, and began going to the Glenrose School Hospital, where she remained for grades three, four and five. In the middle of grade five, one of her doctors asked her if she would like to go back to regular school. Her mother had a very difficult time getting her daughter back into an integrated school setting as the schools within the neighborhood did not feel prepared to accept her. A physio therapist at the Glenrose suggested that her mother try the separate school system, and there the principal was more receptive saying, - "Sure, she can come, she'll be good for all the other students". She continued in that school system until the completion of grade twelve.

She reports that she did not like going to school at the Glenrose, a segregated school as she was not accustomed to disabled persons, who frightened her at first.

The informant indicates that in general she did not feel accepted by her classmates - "there were some people who, at least while we were at school, I did things with -- but on the whole, no, I didn't". She did not feel accepted because she believed that the friendships she had did not develop as much as they could have - "I would wonder why a friendship wouldn't go farther and some of them never did". She felt that her teachers accepted her - "teachers were always pretty good to me in general because they knew I could do the work -- they would always give me a little extra time on tests -- they would involve me in classroom activities". She believes that most of her teachers challenged her to her fullest potential. Within the school system she thought that her high school counsellor was helpful - "she encouraged me and everything -- I could always go and talk to her, so she was pretty good".

The informant took two years to complete grade twelve, as her mother thought this would be beneficial for her, giving her more time to do homework. The informant thought this was a terrible idea - "I was there the whole day, and didn't feel like doing homework and I had nothing to do, was really bored and had time to think about my problems". She then attended a community college to upgrade some of her high school subjects. She attended university, but did not think she had the "mental capacity" for this level and took only one class. She reports that she did not like university, so she went to another community college to take a travel and tourism course. Her motivation for education was to upgrade her skills while she decided what she wanted to do with her life and later, to respond to the advice she had always received "go on and get a good education". She finally decided to learn specific skills for the work force rather than continue general education - "I certainly didn't continue cause I was driven by any great force".

Medical and Related Services System

She has been hospitalized a number of times, twice for brain surgeries, and several times for muscle and bone surgeries. During one of her brain surgeries, she reports that complications led to her having a stroke on her right side, which she considers helpful - "In a way that helped because of the very, very tight condition I was in, I was in a lot of discomfort and that went away with the stroke". During another surgery there was another complication. Her right arm and shoulder before the surgery were normal, but after she woke up from the anesthesia, her right arm shook, and continues to do so. She has also been hospitalized to be tested for different medications which may be helpful to her condition. Overall she believes that these hospitalizations have not affected her - "nothing negative, you know I never really thought about it".

In terms of the way medical personnel have treated her as a person, she feels that doctors have not treated her very well - "you know doctors especially who don't know much about dystonia think well, try this drug. They never seem really interested, and it's you that knows about your body, it's not anyone else, and you try to convince doctors you know that this is happening". She thought that nurses were "okay". With regard to physio therapists, she thought they were pretty good to her, but she did not like therapy, because some of the exercises she had to do caused her a great amount of pain. She reports that she never enjoyed occupational therapy.

The informant reports that she has never liked social workers and feels that some have been rude and condescending to her - "he kind of seems condescending or really rude to me, and I think he thinks I'm only sponging off the government and being a bum -- that's the way he makes you feel".

Employment System

The informant worked part time as a telephone solicitor, and presently works part time at a travel agency. She did not enjoy working as a telephone solicitor, partly because of limited salary. She is very satisfied at her present job - "very good people to work with, they're very fair and equal, and lots of fun to be with". She believes that her disability has not been a problem for her employers or her co-workers. The only difficulty she reports in connection with employment is with her A.I.S.H. payment, as she can earn only a small amount before money is deducted. If her salary increases sufficiently she will no longer receive the A.I.S.H. benefit. In general, she is afraid that her part time employment may have a negative effect on the A.I.S.H. payment.

Social Group System

When she was younger, she felt accepted by her social group but, as she grew older, she felt more alienated and did not feel accepted because she felt that people kept her at a distance. Within the past few years, she has again begun to feel accepted, mostly by the people she has met at the Rick Hansen Center, an exercise gymnasium for individuals with physical disabilities. She feels accepted by this group because of "their attitude - they either have similar problems themselves or have good attitudes to start out with and are used to being around me or want to be around me". She thinks that her friends demonstrate their acceptance by being comfortable around her.

Achievements and Future Goals

The informant feels that she has achieved some level of independence and believes that since moving to her own apartment she has learned to take care of herself better, for example, she learned how to wash her own hair. "I've got to a point where I feel a lot better about myself, happier and outgoing". When asked what she would still like to achieve she reports "not a lot", but would like to keep things as they are. She states that she does not have any "great goals - you do have to realize there's some limitations and what you can do with those limitations, what you can do without". She also says "I just want to be happy, that's all really".

Summary

In summary, this informant appears to have a realistic understanding of her handicapping condition, realizing that due to physical limitations she may not be able to take care of herself or be able to do certain tasks from time to time. Because of this, she sometimes goes through depressions, but she believes that thinking positively will help her get through these periods.

Coping Techniques

Throughout her life, this informant has had many setbacks related to her disability. The coping techniques she has acquired through the years she perceives have developed mainly because of "maturity", and because of the help her mother has given her, "she's always saying well you know think positive, you're not gonna get anywhere otherwise -- she's always telling me to do something -- help(s) me stay in a pretty good frame of mind, I guess". She also believes that confidence has helped her cope. She discusses developing more friendships over the past few years - "making friends -- that gave me a bit of confidence -- that people were finally treating me a bit more like I wanted to be treated, and it just carried off from there".

The informant reports that coping with her disability is difficult when she is going through what she calls "one of her down periods", when her muscles tense to such an extent that it becomes very difficult for her to perform independent tasks, such as getting dressed. "I think I've coped better in the past than I cope now because - like now I'm doing so good that if I have a tight day or a tense day I panic because that reminds me of how bad I've been in the past and I think, oh no, all my independence is gonna go". She reports that she gets "pretty negative" when these times occur but "I have to remind myself, like I truly think that when I start to get tense I concentrate on it more therefore I get tenser, and I think maybe it's more psychological than anything else and I say to myself think positive, think about something else".

In general, this informant's method of coping tends to be taking what life brings her day by day. She mentions that at times she gets frustrated by not knowing what the future holds, because not much is known about her disability, dystonia, and she does not know what her condition will be - "knowing that I can't get too far ahead of myself -- it's kind of frustrating -- all the time I'm saying what's gonna happen in the future, like it's gonna be good and everything -- but then I have to face reality a bit more. It's frustrating. You don't know if you should or shouldn't. Along the way, you have to protect yourself, I guess". This informant appears to cope with her physical condition in a realistic manner.

Case Study #3

This forty-one year old female has chronic polynueritis, one of the neuro muscular disabilities, with an undetermined prognosis - "certainly it is a progressive disability". Her disability was diagnosed when she was two years old. By the time she was twelve, she could no longer walk and got her first wheelchair. Until her early twenties she would walk along behind the wheelchair. At that point, it became physically impossible for her to walk anymore - "I went permanently to the chair". She considers herself to be different from others not because of her disability but because of her individuality - "I hope that I show my individuality as a person and not as somebody with a disability". She believes herself to be an integrated member of society - "because I contribute the same as anybody else, I work full time, I've got a really good career, I pay taxes on my condominium the same as everyone else, I have a very normal social life, very integrated, very normal".

Family System

She grew up in a small town and moved to the city at the age of twenty-five. She has two brothers and one sister and reports that her brothers had no difficulties regarding her disability - "my brothers teased me incessantly". She has recently discovered that her sister is proud of her and proud of what she has done with her life despite her disability. She is still not sure how her mother views her disability - "I think part of it is a natural nurturing that she does with all her children irrelevant of a disability, and the other part of her is the caring part related to the disability". She feels that her mother has coped very well due to techniques she developed through living with an alcoholic, while the informant feels that her father had a very difficult time coping with her disability. Because of his alcoholism, "he felt that he was probably or possibly a contributor to it". Despite this, she feels that he recognized the individuality of each child and realized that she could not meet the physical demands that he had set out for his other children. Overall she feels that her family's reactions were helpful - "they treated me as normal, so it had to be helpful -- I don't think there were any exceptions. I went where they went. I did what they did".

She reports that other relatives were good although - "I think they still sort of feel sorry for me". She feels that some of them are better than others - "probably my peer cousins are better because I think they recognize that I'm doing okay and that I've got on with my life, but there's still some patting me on the head".

School System

Schooling was disjointed. From grades one to six, she went to an integrated elementary school in a small town. Shortly after she began grade seven, she stopped attendance because the school was not accessible, so from age twelve through sixteen she did not attend school. At sixteen she came to the city to stay at the Glenrose School Hospital, a segregated setting for both schooling and therapy. Because of the Glenrose age restriction, at the age of eighteen she left the Glenrose and moved to a room and board situation, living with a nurse from the Glenrose and her family. While living here, she completed her grade nine at an integrated junior high school. She took grade ten and eleven courses by correspondence, and has not completed grade twelve. At the age of twenty-five, she went to a community college where she began first a library science program, dropped out after a few courses, and then began the rehabilitation practitioner program, again dropping out before completion. Now when she thinks back on the schooling she received, she feels angry - "I think I got ripped off because I think we could have challenged the system and made it accessible a lot sooner than we did".

From grades one through six and grade nine she felt accepted by her classmates - "yes, very much so. I was a part of the class, I did everything that the class did". While she was at the Glenrose, she did not feel accepted by her classmates - "the thing is, everybody is so wrapped up in themselves, sort of an isolated little community". During her school years she did her socialization during school hours - "I didn't participate in anything outside of school hours". She perceived that her teachers accepted her - "they were very fair -- they didn't pass me if I didn't deserve it". For the little time she spent in the school system, she thought that her teachers challenged her to her fullest potential.

Within the school system she perceived that no one in particular was helpful with her integration. In her responses though, she does discuss the principal at her elementary school - "I don't think he made any allowance for me. He was just the principal and he knew every kid in the school". She had never considered that it may have been helpful in the integration process that he did not treat her differently.

Medical and Related Services System

While growing up she was not hospitalized for any long periods of time, except for the year and-a-half she stayed at the Glenrose, which is a hospital setting. She reports that the hospitalizations "weren't a major thing in my life".

In terms of the way medical personnel have treated her as a person she feels that "doctors stink". She thinks that doctors are "jerks and they play god -- I don't have a lot of respect for the medical profession because they don't think you know what you're talking about or what's going on in your body and don't recognize what you're telling them". She feels that there is normal conflict with nurses, "some you like better than others". She mentions when she was hospitalized two years ago and was respected by the nurses - "cause I said what I needed". In terms of her interactions with physio therapists, she "negotiates with them now", although she has not received extensive physio therapy. Her attitude to occupational therapists appears ambivalent. In part, she appreciates what they did for her, but she did not fully understand why they were having her perform particular tasks - "they were the ones that instigated me learning how to sew and learning how to cook and that kind of thing, so that was more a positive experience -- also remember doing dexterity lessons and playing Chinese checkers and hating every minute of it".

Her interactions with psychologists had more to do with personal issues than with her disability. She feels that psychologists have treated her quite normally - "the disability is not the primary issue. You know, there may be parts of that that are factors in the way I'm feeling or thinking but it's certainly not the primary issue". Psychologists have "definitely allowed me to feel normal, to not feel special, to not feel different than anybody else".

Employment System

She has worked part time for parks and recreation as a librarian, and later worked on a project at a community college. The latter position led her to full time employment with this community college, where she has remained for fourteen years. Presently she works in a program "which integrates physically challenged people. We assist them to learn independent living skills". She has been very satisfied with the jobs she has had and enjoys her present position - "it's very rewarding, I have super people to work with -- I work well with the students -- it's a challenging, interesting, fun place to work. I love it".

She feels that the employers she has had have been very good. When she was hired for her present job, she felt that her employer "was very fair. She was direct. She was honest with me". When the initial interview was over, the employer let her know that she had very good qualifications for the job but she had to check with the other staff members to see if they would be willing to provide extra assistance when required. She has found no problem with this arrangement - "depending on what I wear, occasionally I might need some assistance in the washroom -- but that's a service we provide for our students so in another setting that may not be as realistic". When asked if she had ever felt discriminated against because of her disability, she thought that to be an interesting question - "I'm not sure whether I'd call it discrimination or not. I think maybe I'd call it a lack of knowledge". At times when she is confronted with this lack of knowledge, it tends to irritate her and "I respond sometimes appropriately, sometimes not".

Social Group System

This individual reports that she did not feel a part of a group, other than her family, until she moved to Edmonton at the age of twenty-five. She believes that was when she became an individual and not someone's daughter or sister. Since that time she has felt accepted by her social group and feels that her social group accepts her along with her disability. She reports that she has an equal number of disabled and nondisabled friends and thinks that her friends demonstrate their acceptance by including her in activities and assisting her in gaining access to various locations.

Achievements and Future Goals

She feels that she has achieved a "wonderful life, (and has) made a mark on society". She has "proven to myself and to my family that I can be an equal contributing member to society. I have proven that as a single woman you can work, you can have your own home, you can cope with day to day situations. I have proven you can have healthy relationships with people, friends, peers (and) family. I have proven that you can travel (and) I have proven that you can have a healthy, normal functioning job". In the future she would like to work in the field of death and dying. In terms of short term goals, she would like "to pay off the condo and do more travelling, I would like to see more of the world".

Summary

The informant recently took a life skills course, and in this class each person had to do a self-portrait. In this exercise, she divided her life into three categories, age one to twenty-five, twenty-five to forty and forty plus. She felt that the period from ages one to twenty-five was "prison term, when I was sheltered, I had no control, everything was very, very much a protected situation". For age twenty-five to forty "I ran, because I didn't have anything. I ran, I learned, I was on every committee, I took courses, I worked -- I had one way relationships because nobody was gonna tie me down. Nobody's going to stop me from gaining everything I can gain because I lost all this time". At the age of forty she feels that she stopped running, "I decided I learned a lot, I had a lot of good skills and I was doing okay, and I think this is my tie to relax and enjoy life and have fun".

Coping Techniques

In learning to cope with her handicapping condition, this informant states that she did grief exercises when she was going through a regression, which includes a lot of crying and going through various levels of loss. She feels that now this process is shorter - "like I will maybe grieve or feel very sorry for myself for a day or two, snap out of it and say okay, you've done this before, how can you compensate for this, so it's a lot shorter process because I've experienced it more often and I know that there are other resources out there". She also mentions that realizing her limitations and knowing what she can do with them has made it easier because she has developed a base knowledge of what she can or can not do.

When she is in a public setting and encounters an embarrassing moment, this informant tends to cope by becoming angry, and at times will start to cry. She mentions that she has these emotions in order to "get rid of embarrassment and the anger". Once she has done that she believes she can begin to "solve the problem". If an embarrassing moment occurs when she is with friends, the informant tends to either laugh about the situation, or will talk about it with her friends. She does not get angry and does not cry if she is with friends because she realizes they are there to help her if she needs assistance. She believes that her friends have helped her the most in learning to cope with her disability and she feels that her coping skills have developed because of necessity and with maturity.

Case Study #4

The informant is a thirty-nine year old male who has cerebral palsy and who did not breathe for the first twenty minutes after birth. It should be noted that there are varying degrees of cerebral palsy. This individual uses a wheelchair most of the time, he is very spastic and he has a severe speech impediment, as his speech is usually not understandable to strangers. He and his family lived in Calgary until he was twelve, when they moved to Edmonton. In terms of special services which were helpful, in Calgary he attended the cerebral palsy clinic, and in Edmonton, he attended the cerebral palsy clinic, and later, the Glenrose School Hospital. He mentions in his biography that his parents "helped to get the first cerebral palsy clinic going in 1954". He does not feel that he is different from other people, "other than for my physical disability", and believes that he is an integrated member of society.

Family System

Besides his parents, he has one brother and one sister. He found that his family's reaction to his disability was helpful - "they accepted my disability right from the beginning". He feels his mother being a nurse helped because "she was used to helping people", and he reports that his parents helped him to become an integrated member of society - "they always took me out, shopping, holidays, camping, everything they did, every place they went, which I think really helped me". He mentions that his brother and sister were helpful in this area as well - "they always took me with them to different activities that they were involved in". Other relatives live in Calgary or Medicine Hat so he does not see them very often, but "they always treated me okay".

School System

Until the age of twelve, this individual's schooling was minimal. During this time, he and his family lived in Calgary, where he attended the cerebral palsy clinic for both therapy and school, with only "about 20 minutes of schooling a day". At the age of twelve, he states that he had only a grade two education. When the family moved to Edmonton, he attended the cerebral palsy clinic for two years, which had a full day school program, and then, with the amalgamation of the school with the Glenrose, he began attending the Glenrose School Hospital, completing his grade twelve.

He feels that teachers have accepted him throughout his school career - "all really helpful -- always talked to me". He also perceives that his teachers challenged him to his fullest potential and passed him only when they felt he deserved to - "when I wasn't doing something right they always told me -- some people with disabilities were allowed to pass without deserving to, which I think is wrong". He states that he was accepted by his classmates - "because I was allowed to participate". At college he also felt accepted by his classmates - "once I get to know them, they get to know me -- they are very helpful -- they even took notes for me". Both his classmates and social group demonstrated their acceptance by the way they reacted to him. He thinks that others show acceptance by being "friendly, helpful (and) cheerful". Nonacceptance is characterized by not talking to or physically avoiding him.

His schooling was a combination of segregated and integrated settings. He attended a segregated school until he completed grade twelve, then went to an integrated setting for some college courses. The informant believes that sometimes segregation is better for the disabled person - "depending on the disability, depending on how much help they need, how much more treatment and how much more time they need from teachers to get a decent education". He thinks that if a disabled person "can handle integrated schools, fine, and if they can't, then a special school is better for them".

After completing grade twelve, he attended the Community Enrichment Project at Grant MacEwan College - "which offers life skill education to persons who have physical disabilities" and, later, he took Accounting 30 by correspondence. Although he was able to complete most of the lessons, he was unable to finish the course as "the work was too difficult on an electric typewriter". Later, this problem was solved when he began using a computer. He enrolled in the General Arts and Science program at a community college and completed several psychology and sociology classes for personal development. Then he enrolled in a computerized accounting program at the P.H.O.E.N.I.X. Training and Development Foundation, which was a computer school for the physically disabled. He was about to start work at P.H.O.E.N.I.X., when it closed due to a lack of funding. Later, he took another computer accounting course, this time at Grant MacEwan College. The informant took these courses to improve his skills, and to increase knowledge - "I love to learn".

Medical and Related Services System

While growing up, he recalls being hospitalized only once, for one day, with a dislocated thumb. He states, "I've never really been sick that much". He apparently did not consider school in a hospital setting as hospitalization.

In terms of the way medical personnel have treated him as a person, he saw little of doctors and nurses. By the time he went to the Glenrose, he had finished working with physio therapists. He thought that they were okay - "after I learned to walk, at age five, I really wonder if it was a waste of time". He also wonders if speech therapists really helped him, and has no opinion on occupational therapists.

His interactions with psychologists occurred during his school age years. After he and his family moved to Edmonton, his parents wanted him to go to the cerebral palsy clinic for schooling. A psychologist tested him, to decide whether he would be able to attend the school, and recommended to his parents that he go to a school for the mentally handicapped. He says, "the only reason I got into the classroom was because the teacher said I could try it". Once he started going to school, he passed every year until he graduated. He feels "if I hadn't gotten that chance, I probably wouldn't have gotten an education".

Employment System

He mentions working for one or two small companies, putting their finances on computer and doing their accounting, and has enjoyed this. Because he has worked little, he did not comment on employers' attitudes. He works at home.

Although he has not had extensive employment, this individual has remained an active participant in society. He has been or is a member of a number of boards, including the Alberta Cerebral Palsy Association, of which he was president. He has been a member of the Cerebral Palsy Association and a member of the Alberta Committee of Disabled Citizens.

Social Group System

The informant feels accepted by his social group - "because I was allowed to participate". He perceives that his social group demonstrates their acceptance by being "friendly, helpful (and) cheerful". He believes that persons demonstrate nonacceptance when they "don't talk to me (and they) shy away for awhile". He thinks that he can help his social group become more accepting - "I talk to them and they get to know me".

When he is in a social setting, he realizes that some people feel uncomfortable because of his disability and his speech impediment - "I realize they probably think I'm retarded or something, but I try to change that by talking to them or just ignoring them. I don't get embarrassed because of my disability -- waste of time".

Achievements and Future Goals

This individual thinks he has achieved "lots in my life". The achievements he mentions are "sitting on different boards, travelling the world through track, meeting people from all different countries". He says, "I feel satisfied with my life so far". He would still like to work more, and would "like more challenges".

Summary

This individual throughout his life has remained active. He has competed in disabled sports on an international level and has participated in wheelchair square dancing, performing across Canada and the United States.

As mentioned previously, this individual has been a member of many boards which help the disabled community. He believes "that a person who has a disability should get involved in disabled consumer movements and other associations who are involved in trying to better the life styles of persons with disabilities, because we are the ones who benefit the most from their accomplishments".

Coping Techniques

This informant perceives that his coping skills in living with a visible difference have changed through education. He believes that the psychology courses he has taken have taught him "how to communicate effectively with others, how to think about other people, how they react with different situations and how I react to others". He tends to cope with any frustrations or difficulties with other people by talking to them and communicating thoughts and concerns. He mentions that when he is out in public and an embarrassing moment occurs, he does not get embarrassed. Overall, he perceives that he has had a good attitude about himself and his life, and has always been able to cope - "I didn't have any big problems that I can remember".

Case Study #5

The informant is a twenty-one year old female with moderate osteogenesis imperfecta. At present, the condition is non-degenerative. A critical period for most breakages seems to be before puberty, "you have this period when you're seven that's just hellish". During her preschool years she was able to walk with little or no aid and now she is either ambulatory with a walker or she uses a motorized scooter. She perceives herself as different, more because of family origin than medical condition. She believes herself to be integrated in settings which are accessible to her and with "people (who) are open-minded and don't judge me based on my disability". She does not believe she is integrated in inaccessible settings.

Family System

In her initial family, she reports that her parents and her two siblings had osteogenesis imperfecta. There was an age gap between her and the next oldest sibling of approximately ten years. She credits this sibling with helping her to learn patience and acceptance of her physical condition. In this family, she was thought of as "the baby" and had virtually no demands or responsibilities placed upon her. The parents had very limited resources, which appears to have led to a parenting style that was laissez-faire.

She lived with various relatives and in foster placements from the age of five to nine - "(it) felt temporary, like being in a hotel". While living in foster homes, she reported feeling like a traitor because she was waiting to join a different family.

At the age of nine, she became a permanent member of another family. In this family she was the oldest child, had specific responsibilities and chores and was expected to participate fully in the family unit. She perceived herself to be the leader of her siblings - "I loved being the ruler -- I loved being in control".

In this family, she felt that her physical disability was a "pre-occupation for almost the first two years". Her parents insisted on her being able to walk, which led to extensive stress fractures due to excessive exercise and to her having to use aids to walk. She mentions that she became mentally exhausted from physical strain.

She discussed coping with the change in families passively - "(I) have come to accept what cards I've been dealt with". She began to have nightmares after moving in with her second family, which she still has periodically. She perceives this to be some type of coping mechanism. Within the second family, her parents were well-educated, which may have led her to focus on schooling as another method of coping. she says, "I turned into a bookworm".

School System

In grade one, her teacher did not allow her to play outside, but kept her in at recess, when she was given special things to do. She though that "it was a great privilege", but when she moved with her second family, this type of treatment was no longer seen by her as positive, but became "isolating".

Throughout her schooling, she generally did not feel accepted by her classmates, and during her school career she felt that only three teachers accepted her. She felt that most of the teachers did not even know she was there - "I wasn't acknowledged as a human being". She perceived that because the teachers treated her differently, her classmates were nonaccepting. "Kids really notice when adults treat a kid differently and take a cue from it". She discusses her lack of friends outside school and her classmates being her social group, when she chose to participate in activities. She states that she only got along well enough with two people to consider them as friends. Overall, with regard to her classmates and social group, she "just thought they were stupid, because I guess I'd pass their stage of development -- was like apples and oranges, we just didn't mix".

She perceives that "elementary school was pretty good, junior high was really bad and high school was tolerable". She feels that her junior high school was inaccessible and the teachers were not very accommodating to her special needs. She thought high school was more tolerable because the school was more accessible. She enjoyed elementary school because she felt the teachers occupied her time, she was challenged intellectually, and - "I felt I had a role to play in class -- I was an important player in the class". Overall she did not feel satisfied with the schooling she received because she felt she was not challenged enough and "didn't learn as much as I could have".

At present, she is in her fourth year of a Bachelor of Arts degree at the University of Alberta. "Almost my sole motivation to go to university was to get out of that town and do something for myself and prove to them all that, yes, I was as good as they were, if not better". At university, she reports that she has participated with the Students Union, been a peer counsellor, a crisis intervention worker and has worked for various career fairs. She participates in activities, both in and out of school, with people she has met through her involvement with different organizations.

Although she perceived her experiences in school to be largely negative, she believes that these experiences helped her integration into society because "it gave me a big taste of reality".

Medical and Related Services System

Due to her physical condition, she has been hospitalized many times, mostly with bone fractures and for surgeries. Most surgeries were for rod and pin placements, and two surgeries were corrective for scoleosis.

Because of the extensive time she has spent in the hospital, she mentions that she feels very familiar and comfortable in that setting. She feels that her hospitalizations have made her more manipulative, - "have to be very creative to get attention".

She feels that some doctors treated her life a "guinea pig" because of the rarity of her disability. She loved nurses and the way they treated her and mentions that she became very attached to some of her nurses because they were her "replacement (for family) kind of thing". Because her family lived in the country and she was hospitalized in the city, she would only see them when they dropped her off at the hospital and when they picked her up to go home after the hospital stay. She had physio therapy during her hospital stays. The rest of the time she exercised at home at the pace she and her parents set. She did not like physio therapists because she felt they were "pain specialists".

Two years after she joined her second family, her parents had her tested by a psychologist. She reports that her reaction was "they must think I'm crazy, they're having me tested for all this stuff". She thought that others were crazy because she was asked to draw stick men and "look at ink blots and tell stories". She perceived psychologists not to be very helpful and was not too responsive to them, "ask me a stupid question and I'm gonna give you a stupid answer and I'm gonna rig the test -- it was more of a control thing". She felt that even if she did tell them what she was thinking, they would not understand what she was talking about.

Before moving in with her second family, she had numerous contacts with social workers. She felt they treated her as a case and not as a person. She felt continuously shuffled from one social worker to another and never knew who her social worker was. She also thought her social workers were too busy to even know if she was integrated or not, and they "basically wanted to make sure I was sleeping under a roof, had food in my mouth and went to school in whatever grade I was supposed to be in and that was enough".

Employment System

The informant has worked for Hire-a-student, both in the small town she comes from and in the city. She also worked part time as a library assistant in the small town. Overall, she feels very satisfied with the jobs she has had and feels that "they've been my best experience probably ever, in a public setting". She has enjoyed her jobs because they have been very productive and she feels that she has contributed within the work environment.

Overall she feels that the employers she has had "have been awesome, just great". She perceives them to be well-educated people who have worked with disabled individuals, or who are very open minded people willing to try new things. She discussed that within her job now she "markets" disabled people in the work force and "as a whole I find employers not always so receptive. They're a little bit scared of the unknown. A lot of them haven't been exposed, and it's not that they're discriminatory or ignorant people, it's that they don't know how to deal with it and they just need to learn and be educated". For the most part she feels that her disability has not been a problem for her in getting a job, but at times she discusses her feeling that she has been discriminated against because of her physical condition, for example, in not getting a job because she could not reach the xerox machine. She copes with these types of problems by "trying to find solutions".

Social Group System

Throughout most of her life, this individual has not felt accepted by her social group - "I'd have to say no for most of my life". While going to school, she considered her classmates to be her social group - "that was the only people that I saw, basically". She did not feel accepted by this group because of her disability - "because kids in junior high and high school focus on health. They're different from other people, and I never fit into anything really". She began to feel a part of a group when she started university and integrated with other students in her residence. She felt a part of this group because of their acceptance - "they got to know me really well for who I really am, and some of them were in some of my classes so we studied together. We lived on the same floor, so we were basically together all the time". She also felt accepted because they included her in activities, while at the same time realizing her disability may cause limitations. She perceives that persons demonstrate nonacceptance by not including her - "by ignoring me and just making assumptions about what I can and cannot do, and thinking about what I can't do all the time".

Because of the changes in her life while she was growing up, she feels that she has a quiet personality - "I think because of the way I am and the way I've grown up and -- (I've) come to live more within myself and vicariously through other people". Because of this she believes that she is not socially mature - "sometimes I compare myself with other people in my age group and think maybe I'm not socially with it". She thinks that she needs to develop herself socially - "I think I could be more social -- I think that's probably what I'm trying to work on -- functioning socially within my age group and learning more social skills than I know".

Achievements and Future Goals

In terms of achievement she reports that she has achieved independence - "cause I live by myself. That's my proof". Another achievement that she expects will be completion of her degree. In the future she would like to have a successful career, in an executive position - "being a manager of a Canada Employment Center". She reports that if she is not being rewarded within her job, law school would be her immediate alternative. She also mentions that one day she would like to get married and have children. She feels that family is important and that having a good relationship with a marriage partner is important to being a person.

Summary

In summary, this informant appears to enjoy being in control of situations, in control of her environment and in control of her interactions with people. Several times in the interview, she discusses being the 'first' in a number of situations, such as the first disabled person in all of her schools and the first to live in residence at university. She feels that she is paving the way to making life easier for other disabled people and this appears to be important to her. It should be noted that all information given in the interviews is included and no judgement made on the accuracy of the information given.

Much of this interview concerns the informant's early family life, the difference in expectations of her two families and her satisfaction at being admired by the younger children in her second family. It should be noted that she is one of the younger of the persons interviewed within this study.

Coping Techniques

This informant believes that focusing less on her disability has helped in the development of her coping skills in living with a visible difference. She believes that her quality of life does not depend on whether she can walk. She thought that being normal meant being able to walk, before she realized that normalcy was "playing with my friends, going out and stuff like that". She perceives that changing her definition of normalcy has helped her in coping with her handicap.

If she is out with friends and there is an embarrassing moment, she at times will talk to the friends about the situation, or she will try to ease the tension - "I laugh it off. I make fun of myself sometimes. I make it more into a joke than anything". If she is alone and she does not know the other person, she will ignore them. She believes that persons who embarrass the disabled have the problem, and she does not want to expend the energy to deal with them. In terms of coping with daily frustrations, she confides in close friends. The informant believes that she has taught herself how to cope with her visible difference, at times by escapism - "I've always found escape in television and books ... I also find escape in school. I lose myself in school". The informant also discusses escaping into a fantasy world - "I was my best playmate. I always played by myself. I always had imagination enough for about five kids". The informant believes that her older sibling from her first family taught her how to cope with her handicapping condition by teaching her patience - "She taught me a lot about being patient, as in having to lay still and denying myself to do certain things because of my physical limitations".

Case Study #6

The informant is a twenty-three year old female with spinal muscular atrophy, a congenital condition. She mentions that her disability at the present time is "pretty much in remission. It's had some setback, when I had the back surgery or when I go under anesthetic, I tend to get weaker". Basically, she does not perceive herself to be different from others - "not normally, well maybe physically, but I feel just like anybody else -- physical barriers make it difficult - but other than that, I don't see myself as any different than anybody else". Most of the time she feels she is an integrated member of society - "except times when you have to sit in separate sections as everybody else".

Family System

This informant has lived in Edmonton all of her life. Her parents were divorced when she was a baby and both parents remarried, with each having two more children, so she has four younger half siblings. While she was growing up, she lived with her mother, who, she reports, always encouraged her to be independent. She mentions that her parents' reaction to her disability was helpful, as she felt "they've always given support when I've attempted to try something new". She believes that the two siblings she grew up with were more accepting of her than her other two siblings - "the brothers that I grew up with are much - they're very accepting of my disability, it's almost like they don't see me as disabled, whereas my brother and sister with my dad whom I didn't grow up with, they see me more as disabled -- they tend to focus on what I can't do", although her second step-brother had no trouble accepting her, because his mother is also disabled.

She reports that other relatives have "always been great -- they treat me like anybody else -- if I need anything they give me a hand".

School System

This individual's schooling was in both integrated and segregated settings. From kindergarten until grade six, she attended the Glenrose School Hospital, and then was integrated into the public school system. In the integrated elementary school "I repeated my grade six because with the Glenrose program, of course, they don't challenge you to what you should be doing and I was behind, so I ended up repeating my grade six". She completed junior and senior high school at integrated settings. While she was at high school, she periodically attended the learning assistance center, which allowed her to have help with her homework, and to have extra time to write exams. She needed a scribe during exams and classes, as she does not have enough muscle strength to write for long periods of time. Now she is in her second year of university. The informant stated that she may take a year off university, as she finds it too physically draining to keep up with the work load.

In elementary and high school she felt accepted by her classmates, but she did not at the junior high school level, when she began to feel different from others - "junior high -- that was the only time I've really felt different". She reports that she did not feel accepted by her classmates because she believed that she was excluded from their activities - "like going out, doing the party thing -- I wasn't invited to parties and stuff like that". She felt accepted in high school because she was invited to parties and other activities, although perhaps less often than other classmates. She felt teachers at the Glenrose accepted her, but some of her teachers in junior and senior high did not - "I had this one particular teacher in computers who didn't want me in the class because she didn't think that I would be able to keep up with the computers, but she hadn't given me a chance". She thought that most of the time, her teachers challenged her to her potential.

Within the school system, she found her aides and high school counsellor helpful, the aide in typing papers, and in meeting her physical needs. She also reports that the aide helped in getting her included in classes and in getting special equipment which she needed - "I guess apparently my aide really fought behind the curtains for me". She considered the high school counsellor to be helpful in encouraging her to try university and arranging for her to have extra time to write her departmental exams. Some teachers were helpful - "they were good at getting notes for me when I needed notes -- making sure that I could get to the - like if they were going on field trips, if I could get there okay".

Medical and Related Services System

Due to her physical condition, this individual has been hospitalized many times, twice for spinal fusion surgery, and frequently for pneumonia. She reports that the hospitalizations have not affected her emotionally, but they have effected her physically - "surgery, it made me weaker".

In terms of the way medical personnel have treated her as a person, she reports that doctors have been alright "most of the time". She feels that doctors tended to treat her as a "guinea pig - because of my disorder, I was one of the stronger people -- they used me a lot for different types of new surgeries and new procedures and braces". She feels that her second back surgery was not necessary - "that kind of makes me angry in that sense -- because I had lost more strength". She perceived doctors are getting better - "I think they're starting to get the message that disabled people are not just a thing, you know. They are people and they're human beings and they all have individual needs". She feels that most nurses are good - "they're really nice and they're really friendly. They treat you like a person, and then there are other nurses that have been doing it so long, they've almost become cold and it's almost they're - unfeeling". She reports that she has always liked physio therapists - "I find them - especially now that I'm an adult, to be really sensitive to what your needs are - they seem to ask you what you need more than telling you what you need". She mentions that when she was younger, physio therapists would tell her what she needed. She feels that physio therapists have "gotten better". She finds occupational therapists to be somewhat helpful, although "sometimes I don't think they always know what they're doing".

The informant reports that she interacts with a social worker she met while living at the second group home. She feels that he has been helpful in teaching her to live independently - "he comes over every once in a while and talks to me about what I need".

She finds that her interactions with her social worker now are more social, whereas previously she perceived him as an advocate - "if I've had trouble getting through to agencies or something, he would go and speak for me".

Employment System

She reports that she worked for a couple of months at a store, in the store room, as work experience for school. Although that has been her only paid employment, she has done considerable volunteer work. She wishes that she could have more experience in the work force - "I'd like a paying job -- I wish I had more experience in jobs". Because of her lack of work experience, the informant finds it difficult to comment on employers' attitudes - "it's really hard to say, like I say I've never really got a paying job -- nobody can really complain with me doing volunteer work".

The informant worries that if she does get a paying job, she may lose the assistance she requires, such as her live-in aide. At the present time, she does not believe the assistance system for the disabled is fair - "when I do get a job, I do want to keep my full time aide, and with the way the government is set up I won't be able - either I work and not have a full time aide because they'll start deducting from my paycheck, so it makes you wonder whether it's worthwhile working". She states that once she is out in the work force, she is going to have to challenge the system which is already in place and will have to fight to keep her full time aide. She thinks the government should pay for her aide, and she should pay the rest of her living expenses with her salary.

Social Group System

This individual reports that she began to feel part of a group when she was at the Glenrose and says that was where she had a lot of friends - "I was comfortable when I was at Glenrose". She felt accepted by this group because the other students at the school had some type of disability - "no worry for acceptance, there was no need, because everybody was so much alike, everybody was disabled, so you weren't really disabled because everybody else was disabled".

Throughout her life, she has felt accepted by her social group. In her childhood she felt accepted by the other children in the neighborhood - "friends around the neighborhood -- they accepted me -- kids ask questions, and once they get their answers, they're fine and they're very accepting". She believes that her social group generally accepts her along with her disability - "my friends wouldn't be my friends if they didn't accept me, and they probably wouldn't be around very long". She thinks that persons show their acceptance by the way they react to her, and demonstrate nonacceptance by not including her in activities.

Achievements and Future Goals

This informant reports that she has achieved independence, "I'm living independently", and perceives this as her major achievement. Another achievement is that she has been able to attend university. One achievement of which she feels very proud is being on the board of Catholic Social Services - "I find that a really big achievement". In the future, she would like to have a job which provides a "solid income". She would also like to have a family of her own one day.

Summary

As mentioned previously, this individual perceives her biggest achievement to be independent. She began to achieve this at a fairly young age when she moved out of her mother's house into a group home at the age of fifteen. She believed this to be a transition period, moving from letting her mother do everything for her to doing things on her own with little assistance from her parents. After living in her first group home for two years, she moved into an adult group home, where she lived until she was nineteen. At that time, she moved into an apartment with a live-in aide. Although she requires full time assistance, she perceives herself to be independent because she is the one responsible for getting the services she requires, such as government assistance to pay for her aide. She perceives herself to be independent because she feels in charge of her own life.

Coping Techniques

This individual believes that becoming more independent has helped in the development of her coping skills in living with her disability. She believes that throughout her life there has never been anything that she could not handle or any situation that she could not overcome, for example, if she notices that people are uncomfortable around her, she will try to ease the tension - "I'll talk to them or I'll crack a joke -- if you say something really funny, people will tend to relax and then it makes it a bit easier". In her everyday life, if something is not working out in a way that is beneficial to her, she will try to change it - "I'm always looking for new solutions to problems if something doesn't work for me". She believes that learning to do more for herself has helped her confidence level, which in turn has helped in the development of her coping skills - "I've gotten more confident -- I'm able to handle things -- I've gotten more ideas now on how to do things, whereas when you just start out, you really don't know what you're doing yet, but by the time you get to the point where I am now, you've got more resources -- you're able to see more ahead in the future of what you should do".

While she was growing up, the informant at times tended to cope by withdrawing, as when she did not feel accepted by her classmates or her friends - "I read a lot when I was a kid". Now the informant tends to cope by talking things out, and finds that she needs to do this quite often because she has a live-in aide - "you have to either work it out or you have a no win situation". She finds that constantly living with someone who works for you can be frustrating at times, but being able to communicate with the other person helps cope with these frustrations - "it's almost like a marriage -- it can be trying at times, you know, because there's always gonna be conflicts". This individual tries to cope by using communication in various areas of her life.

Case Study #7

This informant is a twenty-four year old female with cerebral palsy, which is non-degenerative. She generally uses canes, but at times needs to use a wheelchair, mostly because of arthritis which has developed over the past year. She has some spasticity, and does not have a speech impediment, and mentioned that the cerebral palsy has effected her eyes. At present, she does not believe she is different from other people, whereas in the past she has - "yeah, sure, cause everybody would make - you know when I was a kid other kids would make you feel different, but I'm really not now". These feelings of being different began when she started school. She perceives herself to be an integrated member of society because "I'm doing everything I've ever wanted to do". She believes herself to be integrated because of all the help she has received from people all of her life to become integrated, and because of her individual status - "I'm a mom and I feel that I am integrated -- I wouldn't think anything else ... everybody was pushing me in the direction of integration, and now it's just sort of I don't think about whether I am or whether I'm not, I just am".

Family System

She has lived in the city all of her life. Her family system is made up of her parents and two brothers. She believes that her older brothers have had some difficulty coping with her disability - "because mom and dad sort of doted on me I guess, and took care of me, so they were kind of by themselves for awhile while they took care of me ... they were quite jealous". As she has gotten older, her brothers have been very supportive of her, and one of her older brothers is almost a father to her. The informant reports that her mother had a difficult time coping when her daughter was younger - "when I was born I was a twin, and my twin died and I survived, and she had a hard time dealing with the fact that she could have (only) one baby". She believes that her disability has been a source of confusion for her father - "like he didn't know what to do, if he should do anything or to touch me or not to touch me or what". Her mother encouraged her to ignore unkind remarks, as these did not reflect who she was, and both parents encouraged her to try new things. A brother frequently would accompany her in her initial experiences. Overall, she feels that her family's reactions were helpful - "my family was very supportive in getting me involved". Other relatives have never been a factor in her everyday life, as she and her immediate family have no relatives in Edmonton. At present, she is married, and has a two year old child.

School System

This individual's schooling was in an integrated school setting. She felt that going to school in an integrated setting was a privilege, "cause some kids were put in Glenrose and they weren't given the opportunity to go to regular school". Throughout her schooling, she generally did no feel accepted by her classmates, especially in elementary and junior high school. She began to feel more accepted by her classmates in high school - "high school was alright ... you just went and they talked to you, and if you were free on Friday night then you'd go with them, and if you weren't - they'd ask anyway and then if I didn't want to go I could say well no I can't do that or no I can't go or whatever, and they'd leave it up to me rather than just excluding me from the beginning. She believes that her teachers "never treated me any different than anybody else. I was expected to do my homework and answer questions and do everything else". She has also felt that her teachers challenged her to her fullest potential. She believes that she did not live up to her potential - "I got lazy". Overall, she has been satisfied with the schooling she has received.

After grade twelve the informant went on to college for two years. She took one year of early childhood development, but was unable to complete the course due to illness and had to withdraw. After she recovered from the illness she re-entered college, this time taking general arts. She completed one year of this degree before withdrawing, thinking that as she had spent the previous sixteen years of her life in school, it was about time to get some life experience. The factor which led her to continue her education was her father - "he kind of drilled it into me, keep going, cause he -- my parents, neither one of them graduated high school because they both had to work, so I guess it was really important to them that I go as far as I could".

Medical and Related Services System

This informant recalls being hospitalized many times in the early years, before the age of six, and had a number of surgeries, to lengthen muscles and for her eyes - "cerebral palsy has effected my eyes so I've been in for a few eye operations". After the age of six she does not recall being hospitalized often and does not believe that the hospitalizations have effected her.

In terms of the way medical personnel have treated her as a person, she reports that doctors have not been that good. She feels that doctors tended to ignore her, directing all conversation to her parents - "finally my mom and dad said hey, you know it is her body, you better talk to her about it". As she has gotten older she has tried to avoid doctors. She feels that nurses have "always been really informative". She reports that she never really liked physio therapists, because they made her exercise. She interacted with occupational therapists when it was thought she might go blind, and believes that occupational therapists were good to her.

The informant reports that she does not like the social worker she has now, as she feels that he asks too many personal questions. She alleviated the problem by talking to his supervisor, so now she deals with the financial clerk, who issues her A.I.S.H. (Assured Income for the Severely Handicapped) cheque.

Employment System

The informant has worked part time as a telephone solicitor, and has worked as a secretary for her father. Occasionally she still works for her father. She did not enjoy her job as a telephone solicitor because she does not think she is forceful enough to ask for donations over the telephone. She does not think that working for your parent is a good idea - "they expect you to be able to come in at a moment's notice because you're their daughter ... they don't think of you as an employee". She believes that her disability has not been a problem for her employers or her co-workers. She mentions that some people tell her not to put the fact that she has a disability on her resume, but she feels it is better to

be honest, as a visible difference is diffic
I've had a disability". She believes perso
employment. She has refused the work s
stay at home than do a job". She believes
in getting a job, because some companies

Social Group

This individual reports that she di
years old, acceptance coming through dis
group of friends because she did not have
some type of handicapping condition. Sh
she was younger - "nobody wanted to do
has gotten older she has felt accepted by
nondisabled individuals. She thinks that
being friendly, and that persons demonstr
with me".

Achievements and Future Goals

In terms of achievement she repor
same time". She believes it is an achieve
college. One achievement she feels prou
she would like to finish college and get a
want to have another child. Overall, she

Summary

In summary, this informant appea
nonacceptance by her social group and by
surgeries before the age of six, be a detri
family has helped her in the development
encouragement and support when needed,

nce is difficulty to hide - "they've never not hired me because
lieves personality rather than disability is more of a factor in
d the work she has been offered - "I've decided that I'd rather
She believes that at times being disabled can be an advantage
e companies have quotas for minorities, such as the disabled.

s that she did not feel part of a group until she was thirteen
through disabled group activities. She felt accepted by this
did not have to explain her disability to them, as they all had
ondition. She did not feel accepted by her social group when
wanted to do anything with me ... I was different". As she
accepted by her social group, consisting of both disabled and
thinks that her social group demonstrates acceptance by
ns demonstrate nonacceptance when "they just don't bother

als

ent she reports that she has "achieved a lot and a little at the
s an achievement to graduate from high school and go on to
e feels proud of is being a wife and a mother. In the future
ge and get a good job. She mentions that someday she may
Overall, she wants "to keep achieving .. the regular things".

rmant appears not to have allowed setbacks, such as
group and by her classmates, and having a number of
, be a detriment as she has gotten older. It seems that her
development of a strong sense of self-worth, by offering
when needed, and encouraging her to challenges when

appropriate. She believes that a visible difference is not something which should be hidden, and the abilities the individual has should be used to their fullest potential.

Coping Techniques

The coping techniques this informant has acquired through the years she perceives have developed mainly because of her family - "they coped fairly well, I think you learn from what you see to some extent". She believes that throughout her life there has never been anything that she could not handle or any situation that she could not overcome, for example, if she notices that people are uncomfortable around her, she will try to ease the tension - "I make a joke or I joke sort of - I'll be myself, try and get them to relax, I'm not gonna bite them or anything else, so try to get them relaxed". Another situation in which she needed solutions was when she had a child - "I've adapted very well, at first I thought oh no what am I going to do, but I adapted very well - for the first month he slept in a stroller beside my bed so I didn't have to worry about getting him in and out of the crib".

When she is in a public setting and encounters an embarrassing moment, this informant tends to cope by becoming embarrassed, then she will try to ignore the situation - "And I just try to get out of there as fast as I can". If an embarrassing moment occurs when she is with friends she will again become embarrassed, but if her friends start joking about the situation, she will start joking. She finds it harder to cope with embarrassing moments when she is with friends because she cannot leave the situation as quickly as she might wish to.

While she was growing up, the informant at times tended to cope by withdrawing, as when she did not feel accepted by her classmate or her friends. When she was younger she cried a lot, but as she has gotten older she has tended to ignore situations. She believes her coping skills have developed from crying to ignoring because "as you get older it gets easier because people accept you as you are". Now she tends to cope by talking things out, and finds that she needs to do this quite often, because of being married and having a child. Although she does not get frustrated with living with her husband, she at times finds it difficult to live with someone all the time. She tends to get a sense of security from living with her husband - "it's easier to be with somebody that could help you if you ever needed it". If she gets frustrated with her child she will cope by putting some space between them - "he'll go play in his room and I'll just go outside for a few breaths of fresh air and come back in and start all over again".

The data are summarized in Tables 1, 2 and 3.

Table 1

CASE STUDY	FAMILY SYSTEM	EDUCATION SYSTEM	MEDICAL AND RELATED SERVICES SYSTEM
#1	Father believed her capable - tutored her Mother more protective	No difficulties other than hospitalizations Completed high school (4 years) Postsecondary Integrated School principal indirect role model	Hospitalizations - several Little respect for medical personnel
#2	Mother - helpful with integration and access to education and acceptance of disability Sister - not very helpful Brother - accepting Father - somewhat helpful	initial elementary - integrated middle elementary - segregated later elementary - mother had to fight for access to integrated school Junior and Senior High no problem some postsecondary Degree from training college High School counsellor helpful	Hospitalizations - many Enjoyed hospital Doctor - recommended integration Nurses - fine Physios - hated therapy O.T. - not enjoyable Social workers - dislikes attitude
#3	Brothers - no problem Mother - coped very well Father - difficult time coping - alcoholic	Disjointed and varied - age 12-16 did not go to school - inaccessible - integrated and segregated - some correspondence courses - did not complete grade 12 and postsecondary	Hospitalizations - short Dislikes doctors Nurses vary Physios - negotiates with them O.T. - somewhat helpful Psychologists - helped deal with personal issues of disability

Table 1 continued

CASE STUDY	FAMILY SYSTEM	EDUCATION SYSTEM	MEDICAL AND RELATED SERVICES SYSTEM
#4	All family members helpful towards integration -- included him in everything	Segregated Limited - age 12 grade 2 education Some postsecondary courses Teacher decisive in access to education - age 12	Hospitalizations - none Physios - helpful in learning to walk O.T., Speech - not helpful. Psychologist - recommended school for retarded
#5	Complex Family 1 - parents negligent, accepting youngest - no responsibility older sibling - counsellor Family 2 - educationally oriented oldest child - responsibilities	Good except in junior high Integrated In the process of completing a Bachelor of Arts degree Postsecondary	Hospitalizations - frequent fractures and surgery Hospital - familiar, comfortable stays made her manipulative Doctors - made her feel like guinea pig Nurses - loved Physios, psychologists, social workers - disliked
#6	Parents - divorced - step father -- alcoholic - remarried - step brothers & sisters - siblings she grew up with more accepting - stepmother - disabled - eldest child - age 15 moved to group home -- became more independent	Elementary - Glenrose School Hospital Junior and Senior High school - integrated Some University training High School counsellor helpful	Hospitalizations - surgery, pneumonia Became routine Doctors - made her feel like guinea pig Nurses, social workers, O.T. - likes Physios - sensitive to her needs
#7	Mother - very supportive Brothers - at times more supportive than parents - always there Father - supportive - away a lot with work	Integrated Some postsecondary - began two degrees at college, did not complete either	Hospitalizations - frequent as child Doctors - no respect for her - avoids them. Nurses - fine. Physios - disliked exercises, not therapist O.T., social workers - dislikes

Table 2

CASE STUDY	EMPLOYMENT SYSTEM	SOCIAL SYSTEM	INDIVIDUAL SYSTEM Disability
#1	No difficulty Early retirement due to increasing physical limitations	Junior and Senior High School - school activities only Adult - initial - handicapped - later - nonhandicapped	Lower body paralysis Wheelchair Double Ostomy - bowel and bladder Renal problems Degenerative Onset - age 16
#2	Now - works part time - initially did volunteer work Thinks that health problems prevent her from working full time	Growing up did not always feel accepted Past two years developed self-confidence, more friendships Junior High - somewhat accepted Senior High - a bit more accepted	Muscle disorder Wheelchair Degenerative Onset - age 7
#3	Good - very satisfied Employers very good	Felt a part of a group - age 25 Feels accepted - no barriers In-school did not participate in extra-curricular activities Glenrose - did not feel as accepted	Neuro-muscular disability Wheelchair Degenerative Onset - age 2
#4	Now - part time work Would like more work Works at home - uses computer	School - accepted Social group - accepted - once they get to know him Accepted - allowed to participate	Cerebral Palsy Uses a wheelchair Spastic Speech impediment Non-degenerative Onset - birth

Table 2 continued

CASE STUDY	EMPLOYMENT SYSTEM	SOCIAL SYSTEM	INDIVIDUAL SYSTEM Disability
#5	Fair to good. Some difficulties regarding equipment Feels employers generally very helpful Works during summer vacation from university	School - poor Family 2 - feels younger children saw her as leader University - some concern about social skills -- not socially mature - felt accepted by students in residence	Brittle bones Walker/Wheelchair Non-degenerative Congenital Onset - birth
#6	None No paying jobs Does volunteer work Job experience during school.	Social group - accepted Elementary and senior high school - accepted Junior high school - difficult time	Neuro-muscular disability Wheelchair Degenerative Congenital Onset - birth
#7	Worked short time as phone solicitor Works part time as father's secretary Full time mother	School - poor (loner) Developed friends initially through disabled activities Elementary and junior high school - nonacceptance High school - acceptance	Cerebral Palsy Some spasticity canes and wheelchair Non-degenerative Congenital Onset - birth Arthritis - past year

Table 3

CASE STUDY	SELF - PERCEPTION		TIMES OF SEVERE STRESS	COPING STRATEGIES	LIVING ARRANGEMENTS
	DIFFERENT	INTEGRATED			
#1	Yes	Yes	Age 16 - 23 - post-operative - loss of ambulation	Early - anger, frustration Later - acceptance, strong belief in self-sufficiency, deals with life day by day	Age - 48 Female Lives with husband, who also uses a wheelchair Apartment - condo Part time housekeeper
#2	Yes	Yes	Regressions Inability to care for self	Anger, frustration on "bad" days Acceptance of limitations Believes maturity helped in coping Humor	Age - 23 Female Apartment Support Services
#3	Yes because of individuality not disability	Yes	When set backs occur Regressions	Anger, frustration, crying Goes through grieving process when going through regression Humor	Age - 41 Female Live-in "friend" (aide) Owns condo
#4	No	Yes	None	Acceptance of disability and limitations Keeps active within society	Age - 39 Male Apartment Support Services

Table 3 cont'd

#5	Yes because of family not medical condition	Yes - now in some settings	Childhood - change of family - many fractures Age 9 and up - emphasis on walking Junior High School - school inaccessible Poor teacher/student attitudes to her	School - withdrew into school work Sees self as leader, pioneer Enjoys control of others Humor	Age - 21 Female Apartment Minor Support Services
#6	No	Yes - in some settings	Difficulty with aide Access to services	Gained independence - age 15 Finds solutions Talks out problems Withdrew - read a lot during childhood Humor	Age - 23 Female Live-in full time aide
#7	No - not now, growing up yes	Yes	Childhood - feeling of not being accepted in school	Talks out problems Deals with things in straight forward manner Early - cried a lot Later - withdrew	Age - 24 Female Married one child House No Support Services

Discussion of Research Questions

Systems theory supplies a framework for observing and discussing life experiences, identifying specific experiences as part of one system and emphasizing the interrelationships of the systems. Six systems are discussed in this study. The individual system of the informant is defined as the specific medical condition, requiring special adaptations and procedures, including self-perception of integration, times of severe stress and coping strategies. The family system is the family in which the informant grew up and includes family members, family friends, neighbors and other daily associates, as well as family related factors, such as prevailing attitudes in the home and neighborhood, and living conditions. The education system is made up of the factors influencing academic achievement, including opportunities offered, as well as prevailing attitudes demonstrated by school personnel, principals, teachers and counsellors, and the informant's classmates. The medical system includes the hospitalizations and medical procedures the individual may have had, and the prevailing attitudes of the people within this system, doctors, nurses, physio therapists, occupational therapists and speech therapists. The related medical system is composed of the social workers and psychologists with whom the informant may have had contact. The employment system consists of the jobs which the informant has had, and includes employment opportunities offered and job satisfaction, as well as employment related factors, such as prevailing attitudes of employers and other co-workers. The social group system is the friendships and the activities in which the informant is involved.

The discussion section of the research questions first examines findings in the areas of family system, education system, medical and related services system, employment system and social group system. The primary system which all these areas influence is the individual system, which will be discussed last.

Family System

The role of the family is thought to be vital to the integration of the visibly different person. All the informants believed that their families were helpful in some way with their integration, including them in family activities. Four of the respondents stated that their siblings furthered the integration process by including them in leisure activities. The role of siblings ranged from accepting to advice giving. The role of parents seemed to vary, but in general they were perceived as supportive, with the mother's role being central. One informant perceived her mother to be more protective than her father, whereas another informant thought the opposite, as her mother facilitated her entry to an integrated school, by negotiating with different schools until one agreed to allow her daughter to attend. With regard to fathers, one informant reported that her father was an alcoholic, and another reported that her step-father was an alcoholic. One informant believed that her alcoholic father had a difficult time coping with her disability because he felt responsible. Another informant thought that her father was very supportive because he spent considerable time tutoring her with her school work. She perceived her father to be a role model because he was a teacher. Another informant also thought that her father was supportive, but he was away a lot with work, and at times she perceived her brothers to be the parental figures because they were there when she had a problem she needed to discuss. The informant who has lived with two families reported two very dissimilar parenting styles, with no expectations of her in family number one, and high expectations for responsibility and for rehabilitation in family number two. The parents in family number two were role models for her because they were educationally oriented. Another informant discussed how the role of the parent can aid in the achievement of independence. At the age of fifteen this informant moved in to a group home, where she felt she became much more independent, as she went from an environment where her mother did everything for her, to having to learn to do things for herself. The role of the parent can be both protective and challenging, as was the case with one informant whose mother provided support by listening to her daughter discuss how sometimes it was very difficult to listen to other children make fun of her visible difference. Her mother would advise her that she needed to ignore them, and that what the other children were saying did not matter. One or both parents have been very involved with their visibly different child, showing concern over their child's education and integration.

In summary, it appears that the family is central to the development and integration of the handicapped person. Parent expectations appear to the informants to be very influential. Siblings have enhanced the process of integration by including their handicapped sibling in activities, by fostering and encouraging independent activities and by general support and advice. Among these informants, other relatives have not been a main factor in the lives of these visibly different persons, other than to offer encouragement and support periodically.

Education System

Three of the respondents' schooling was entirely within an integrated setting, while four informant's schooling included both integrated and segregated settings. Six informants have completed some postsecondary courses. One of the informant's elementary and secondary schooling was in segregated settings, with postsecondary schooling in an integrated setting. This informant discussed a view that some professionals who work with handicapped people do not support, that at times a segregated setting may be better for the handicapped person, depending on the amount of individualized teaching required and on the amount of time needed. Three of the informants' schooling has been interrupted or disjointed. One informant missed almost an entire year of school because of hospitalization, and another informant did not go to school from age twelve to sixteen because of school inaccessibility. Another informant only had a grade two education at the age of twelve because the clinic he attended offered schooling for half a day. At the age of twelve he entered a full time segregated school setting, because a teacher believed he should be given an opportunity to attempt the school work. Four of the respondents in integrated settings stated that they did not enjoy junior high school because they felt they were not accepted by their classmates. Five of the informants believed that their teachers accepted them, including them in classroom activities and expecting them to achieve to the best of their ability. The respondents did not believe that their teachers made any special adjustments, except for two informants who recalled teachers allowing extra time to complete tests and to move from class to class. Principals were not discussed frequently by informants. One informant mentioned that a principal allowed her to attend his school when no other school in the neighborhood would allow her access, and one informant indirectly considered her high school principal to be a role model in living with a visible difference, in that he continued to participate in a variety of activities and did not allow his handicap to deter him. One informant recalls her high school counsellor was helpful, by helping in setting goals and listening to problems.

In summary, it appears that the education system has also been central in the integration of the visibly different individual. Although at times schooling has been disjointed in some manner, either through inaccessibility of schools or school programs, it does not appear to have had a negative effect on the future goals of these informants, with many attempting postsecondary courses. A major period of difficulty for informants in integrated settings appeared to be during their junior high school years, when they had a feeling of nonacceptance by their social group. The informants believed that generally their teachers accepted them and challenged them to their fullest potential.

Medical and Related Services System

All of the informants discuss poor experiences with medical and related services personnel, although they believed that certain professionals were more helpful than others. All respondents voiced strong reservations about their medical doctors, with complaints ranging from not receiving information on their conditions and the procedures being used, to feeling that the information they provided was regarded as inconsequential. One informant mentioned that it was one of her medical doctors who suggested she re-enter an integrated school setting. Two informants felt that they had been used experimentally, with unnecessary medical procedures being carried out. One respondent attributed her loss of mobility to inept medical intervention, and resented the lack of information on this given her by those responsible. Four informants believed nurses to be helpful, while one informant's opinion varied. One informant mentioned that while she was hospitalized, nurses became the replacement for her absent family. With regard to physio therapists, three of the respondents mentioned that they did not like the therapy and do not have fond memories of physio therapists. Six informants stated they did not see the usefulness of the therapies in their lives. The respondents seemed not to consider that physio therapists may have helped them in their mobility, such as adapting a wheelchair for independent use, or adjusting back braces to reduce pain. One informant thought that physio therapists now were sensitive to her needs whereas in the past they seemed less sensitive. Four of the informants made similar comments about occupational therapists, saying they did not understand the purpose of their role. Again respondents did not fully comprehend how occupational therapists could help them achieve more independence in their lives. For example, an occupational therapist designs wheelchair trays for books and writing materials, or provides training in aids to daily living. Only one informant recognized the help occupational therapists have given her in learning how to live a more independent life. It is possible that the experiences with occupational and physical therapists occurred relatively early in the lives of the respondents, who do not recall the gains made during these therapies. It is possible, as well, that the therapists were not as informative as they might have been on the objectives of the activities conducted with the respondents. Three informants have not had positive interactions with social workers, perceiving that social workers have been insensitive and have not considered their needs. One informant spent a considerable amount of time with social workers and believes they have helped her gain access to services she may require, which has helped her achieve more independence. Only two of the informants mention having interactions with psychologists, one positive and one negative. The individual with the negative interaction recalls that the psychologist recommended he be placed in a school for the mentally handicapped. The individual who has had a positive relationship with psychologists has consulted with them regarding personal issues, which are partly related to her disability. She felt that psychologists helped her to feel normal.

In summary, the informants perceived medical and related services personnel not to be very helpful, although they believed that certain professionals were more helpful than others. The informants had strong misgivings about their medical doctors, believing that they were not given enough information about their conditions and the procedures being used. Opinions regarding nurses varied, from not caring about the individual's needs to becoming a replacement for family. In general, the informants did not see the usefulness of the therapies in their lives. This could be due to therapists not giving enough information to the respondents or to the respondents' parents regarding the objectives of the activities conducted. With respect to social workers, for the informants who have interacted with them, three have not had positive experiences. These informants perceived that social workers have not been sensitive to their needs. Two informants have had interactions with psychologists, one positive and one negative. The individual with the positive interaction consulted with the psychologist regarding personal issues, which are partly related to her physical condition. Four of the informants have had lengthy hospitalizations. Two of the informants stated that they enjoyed their hospitalizations, one because she felt that nurses provided her with a family and the other because of the physical accessibility of hospital areas, and one mentioned that the hospitalizations became routine.

Employment System

The respondents consider that they have achieved some degree of normalcy because they have some level of independence and control over their lives. Independence for some is participation in the work force. Six of the informants have been employed, two of them full-time. Health has been a major factor in the respondents' level of employment. One informant has had to retire because of declining health, while another informant believes that health problems prevent her from working full time. The respondents who have worked do not believe employers' attitudes have had a negative impact on their employment, although one informant mentioned that her possible future employer was not willing to make some areas of the work environment more accessible. Another informant said that when she was being interviewed for the position she now holds, her employer realized that she would require assistance in some situations and her employment depended upon her co-workers willingness to provide that assistance. Three informants hoped to work or to work more hours than they were doing presently.

In summary, these informants have gained access to the training for their preferred employment opportunity when necessary. Only one informant reported difficulty with access to the employment setting. According to the informant, reasonable changes could have been made to the employment setting to make it more accessible. The respondents who have worked do not believe employers' and co-workers' attitudes have had a negative impact on their employment. With regard to employment opportunities, health has been a factor in the respondents' level of employment. Three informants discussed that in terms of future achievements they wanted to become part of the work force, or to work more hours than they were doing presently.

Social System

All informants stated that they felt accepted by their social groups, though they believe the acceptance level varied in different stages of their life. One informant stated that he felt accepted by his social group because he was allowed to participate, while another respondent based her feeling of acceptance on there being no barriers in the activities she and her social group participated. The informants mentioned that they believe themselves to be accepted during elementary school, possibly due to the feeling of 'family' which is developed through the years, because of the amount of time pupils are together. Five of the respondents mentioned that they did not feel well accepted during their junior high school years, but more acceptance was demonstrated by their classmates when they entered high school. Two of the informants mention that they only participated in activities during school hours. Two respondents stated that they worked on the school yearbook and two respondents participated in their high school Students Union. Three of the informants, because of what they perceived to be nonacceptance, spent much of their time alone, with two withdrawing into reading. One informant made her school work the central focus of her life and the social group superficial. Since attending university she has felt more accepted by her social group, although she expressed concern about her social skills as she perceives herself to be socially immature. Four of the informants' school combined integrated and segregated settings, which they believe influenced their level of acceptance. Three of these informants stated that they felt more accepted in a segregated school setting because they were the same as everyone else, though one informant did not feel accepted in the segregated setting because she thought that children in that setting were only concerned with their own needs. All of the informants mention that their social group is a combination of disabled and nondisabled individuals. One informant talks about her interactions with some of her visibly different friends over the past two years which she believes has helped her level of self-confidence increase.

In summary, the informants stated that they felt accepted by their social group, though they believe the acceptance level varied at different age. In general, the informants believe themselves to be accepted during elementary school but not in junior high school. The informants perceived their acceptance improved in senior high school. Three of the informants who went to both segregated and integrated school settings mention that they felt more accepted in the segregated setting because they were the same as everyone else. In terms of believing themselves to being integrated in social settings all of the informants stated yes, although two informants thought they were only integrated in some settings, either those which are accessible or those in which they interact freely. The informants feel accepted when they are allowed to participate in activities or when there are no barriers in activities. For some individuals with visible differences, a time of severe stress is when embarrassing moments connected with their disability arise in social settings. Four informants mention using humor to ease the embarrassing moments, while other informants talk about the situation with their friends so that they may understand the situation.

Individual System

Six of the subjects live in apartments, receiving some degree of aid to maintain a level of independence. The degree of help ranges from having a full time live-in aide to receiving a small amount of aid for light housekeeping duties, with the amount of assistance required depending upon the handicapping condition. Four of the informants have degenerative conditions which may lead to them requiring more assistance than others. Four of the respondents were born with their handicapping condition, while the other three respondents became handicapped between the ages of two and sixteen. All of the informants use a wheelchair at some point in their daily life, although one respondent uses canes to walk part of the time, and another respondent at times uses a walker. The informant who walks with canes uses a wheelchair part of the time due to a second handicapping condition which has developed over the past year, arthritis. Another finding in the individual system is that only two of the subjects are married, and one of the informants has a boyfriend. The other respondents in the study did not mention being in such a relationship. All of the respondents believe themselves to be integrated, although two of the informants discussed this as depending upon the accessibility of the setting. Three of the subjects perceive themselves to be different, two because of their physical differences and one informant because of her individuality, not her visible difference. One informant stated that now she did not see herself as different, but while growing up she felt different. For the informants, times of severe stress include periods of physical regression, one having to adapt to loss of ambulation at the age of sixteen. This period lasted for seven years. For another informant, her time of severe stress was during childhood, when she felt that she was not being accepted in school. A stressful time for one of the informants was when she changed families'. Living with the second family was at times difficult because this family put an emphasis on her learning to walk, which caused her stress fractures. Another time of severe difficulty for this respondent was in junior and senior high school, as the schools were partially inaccessible, there were stairs, and she perceived poor teacher and student attitudes to her. A time of severe stress for another informant is when she has difficulty with her live-in aide, or has difficulty getting access to services. Only one informant states that there are no times of severe stress. The informants cope with these difficult times in various ways. Three mention that they get angry and frustrated, and one of these informants mentions that she goes through a grieving process after a regression. Two informants cope by accepting the limitations of their handicapping condition, and one of these mentions that maturity has helped her accept the limitations. Two informants mention that they cope by talking out problems they encounter with other people and then begin to work on a solution. Two of the informants stated that they have at times dealt with a stressful moment by crying. Another coping strategy three of the informants have used is to withdraw, two into reading and one into school work. One informant copes by believing herself to be a pioneer or leader in the disabled community, and by being in control of all situations in her life. Four respondents mention coping with difficult moments associated with their handicapping condition through humor.

All systems influence the achievement of healthy self-concepts. In general, it might be assumed that having experiences which are seen as age-appropriate serves to support an individual in achieving this. Exclusion from age-appropriate activities in which an individual wishes to participate may lead to lack of self-worth, limited social learning and what frequently is described as poor self-concept. Added to this exclusion, these respondents are visibly different and most must depend upon others for some assistance in various everyday activities, which range from physical care to using the Disabled Adult Transportation System. The area of the interviews which gives most information on self-concept is the question of feeling different or integrated. This has been discussed previously.

Further information which may be related to self-concept is in the area of desired further achievements. Two of the informants mention that one day they would like to achieve a family of their own. One respondent stated that having a good relationship with a marriage partner is important to being a person, she does not think that humans are meant to live alone all the time and she does not believe that people could survive without other people being around to fill our hearts and our lives with experiences, activity and joy. Three of the respondents mentioned that they would like to work more, and although six informants have participated in the work force in some capacity, they would like to earn enough money so that they could live independently without relying upon a variety of government agencies, such as the Assured Income for the Severely Handicapped. A major achievement the respondents would like is some stability in their lives, with the disability remaining stable enough to allow them to enjoy life to the best of their ability and to make realistic plans for their future.

In summary, four of the informants have a degenerative condition, which may lead to them requiring more assistance than others. Four of the respondents were born with their handicapping condition while three became handicapped between the ages two to sixteen. Due to their handicapping conditions six of the informants receive some degree of aid to maintain a certain level of independence. The degree of help ranges from having a full time live-in aide, to receiving a small amount of aid for light housekeeping duties. All of the respondents believe themselves to be integrated, with two informants mentioning that only in some settings do they feel integrated, partially due to inaccessibility of settings. Three of the informants perceive themselves to be different, two because of their physical differences. For the informants times of severe stress occurred in a variety of ways. For two of the respondents a time of stress is when a physical regression occurs. The informants cope with these difficult times by using such strategies as humor, dealing with problem situations in a straight forward manner, crying, withdrawing, becoming angry and frustrated, and going through a grieving process when a regression occurs. Two informants also mention coping by accepting the limitations of their handicapping condition. With respect to the perceived achievement of normalcy, two of the informants mentioned that one day they would like to have a family of their own. Three of the informants mentioned that they would like to work more, and although six informants have participated in the work force in some capacity, they would like to earn enough money so that they could live independently without having to rely upon government agencies.

CHAPTER VI

DISCUSSION AND IMPLICATIONS

The information received from the informants of this study is relevant to the members of all systems discussed. Integration of physically handicapped persons presently appears to be increasing. All members of the teaching profession can expect to have handicapped pupils in their classes and parents of nonhandicapped pupils can expect their children to have handicapped classmates. Medical and related personnel may encounter somewhat different expectations from patients and their families, as handicapped persons live in communities rather than institutions. With better general access to educational institutions, the number of physically handicapped persons entering the labour force is increasing.

Within the first system, family, it is important first of all for parents to have a basic understanding of the child's handicapping condition from medical personnel. Parents may have to insist that they receive this information as sometimes medical personnel are not forthcoming with necessary information. Parents need to know any possible limitations of the handicap so that they may develop realistic expectations for the handicapped child. Not only should parents know the limitations, they should also have an understanding of any strengths of their child to avoid an overly pessimistic viewpoint about their child. Strengths and limitations of the handicapping condition should be known so that parents can then keep activities within the family unit as normal as possible. It is important for parents to include the handicapped child in as many family type activities as is possible to enhance the process of integration. While meeting the needs of the handicapped child, parents need to realize that the needs of nonhandicapped siblings can not be ignored. Siblings of handicapped children can play an integral part in the integration process and are vital in normalizing activities, as they can be role models in the process of socialization for the handicapped child. Inclusion in a variety of social activities may enable the handicapped child to develop appropriate social skills. It is believed that a positive communication pattern between nonhandicapped siblings and parents of handicapped children is important in achieving optimal sibling adjustment. For instance, nonhandicapped siblings may become resentful if they feel that all the wishes of the handicapped child are met while their wishes may be ignored, or they may resent the extra responsibilities given to them because their handicapped sibling cannot take a normal role in responsibility for self or home care. Parents can possibly lessen this resentment by increasing the attention given the nonhandicapped child and by sincerely expressing appreciation for the assistance given. Parents may need counselling on how to develop a parenting style which is fair to the handicapped child, the nonhandicapped child and to themselves.

Families at times may need outside counselling to lessen any stress caused by having a handicapped child in the family unit. Parents may need counselling to lessen feelings of guilt they may have for producing what they view to be a defective child. Counsellors as well as parents need to realize that some feeling of guilt is quite normal, but when the guilt is carried to extremes, problems may arise. Parents' 'normal' feelings may range from love and protection to intense irritation. Although parents of handicapped children may appear to outsiders to be overprotective there is a range of the overprotectiveness, from reasonable to unreasonable. The feelings parents have regarding their handicapped child can affect the parenting style developed. Parents need to discuss the parenting styles which they use, as parenting styles may appear to be conflicting. One parent may be overprotective while the other parent may encourage the child in the integration process. This may not be harmful if parents discuss their concerns and make decisions which take into account both the child's need for development and for reasonable protection. Parents encourage the handicapped child to develop social relationships outside the family unit and give advice on how best to handle situations in which other individuals are being unkind to them because of their handicap.

At times parents may need to seek marriage counselling, as the stress of having a handicapped child can cause problems in the marital relationship. Within the family unit siblings of handicapped persons also may need some counselling, for example if some siblings feel guilty for being healthy or being inappropriately protective of the sibling. Counsellors need to help siblings realize that their feelings are normal, and to recognize that normal irritations between children may be intensified when one child is handicapped. Nonhandicapped siblings may need some guidance on appropriate interaction, which may include not allowing themselves to be inappropriately manipulated. While it may be healthy for nonhandicapped siblings to include the handicapped sibling in social activities, they must recognize that they do not need to restrict themselves solely to activities in which the handicapped sibling can participate. Handicapped children, like others need to develop their own friendships and participate in their own social activities. A counsellor, or a parent, can guide the nonhandicapped child in helping the handicapped child develop the social skills necessary to achieve this goal.

In general, parents provide an advocacy role by using relevant medical information and gaining access to appropriate services which enable their handicapped child to lead a life which is as normal as possible. At times, these services include access to an education program which best meets the needs of their child, and accessibility may require parental intervention. Parents in their role as advocates provide encouragement and support to their handicapped child in attempting new areas of their life, such as going to a new school and developing new friendships. By developing realistic expectations based on medical and educational information, as well as on their own knowledge of the child, parents convey to the handicapped child possible future goals.

When the handicapped child reaches school age, the school and parents, using relevant medical and psychological information, decide on the school program which will best meet the needs of the child. This may influence whether the child is placed in a segregated or an integrated school setting. Many professionals working with handicapped children believe that integrated schools are best for handicapped students. One informant in this study states a different viewpoint, one which is shared by some professionals, that at times a segregated setting may be best for the child, depending on the therapies or individualized attention needed. In deciding which school program will meet the child's needs, school personnel have to decide on the program which will require minimum adjustment to the way in which the work is done, keeping expectations and work load as normal as possible. Reasonable variations may include the number of assignments completed, or the time allowed to complete exams. Teachers are central to the handicapped students' academic needs, and socialization of the student. First of all, teachers themselves need to demonstrate acceptance, by including the handicapped child in the classroom and in as many classroom activities as is possible, although physical limitations may prohibit total participation. It is reasonable to expect that some activities necessary for nonhandicapped students may be unsuitable for some students, for example, gymnastics and basketball. When possible, handicapped students may be given other responsibilities such as score keeping and equipment supervision. With respect to socialization, elementary school activities lend themselves to integration and acceptance, possibly because of the amount of time the teacher and students spend together, allowing a feeling of family to develop. At the junior high school level teachers and counsellors may need to intervene to develop appropriate social interaction among handicapped and nonhandicapped students. Appropriate interventions might include special interest clubs, social skills training and units on understanding and accepting differences. Handicapped students at the junior high school level, with the help of counsellors, teachers and parents, should begin to consider future careers. Consideration should begin at this level because courses chosen at the senior high school level will influence access to postsecondary institutions. Counsellors can guide handicapped students in choosing future careers which they can master academically, can gain access to the necessary training and for which there is future need. School counsellors at the junior and senior high school levels might make sure that visibly different students are aware that they may approach the counsellor on any concern. School counsellors may also be able to assist in the planning of individual education programs and the individual behavioral program. In doing so they provide teachers who have a handicapped student in their classroom with a continuous support system in ongoing concerns.

With regard to medical and related services personnel it was generally found that the informants have some severe reservations. This could be due to the lack of information given to handicapped persons and their families on the medical procedures being carried out and the reasons for these medical procedures. When the handicapped persons are younger, it may be understandable that they are not given in depth explanations on the objectives of medical procedures, but as they get older doctors and therapists should be willing to explain and answer any questions handicapped persons may have. Among any of the persons involved, patients, parents and medical practitioners, frustration and confusion may develop if there is lack of communication. A possible solution to lessen the perceived lack of information being provided by the medical profession would be a medical liaison worker, someone who could explain medical procedures and objectives to handicapped persons and their families and someone who could share concerns and questions these individuals may have with the medical personnel involved. Having a medical liaison person could increase the understanding of all individuals involved. Several of the informants felt therapists were more co-operative with them as adults than as children.

With respect to employment, generally it was found there were no major problems described with access to the work place and with the attitudes of both employers and co-workers. The informants in this study felt they attained appropriate training for their jobs. Overall the individuals who have been employed express job satisfaction. The only wish they have is that they could work more and be able to work more hours in a day. A major factor with the employability of handicapped persons is their health, which may limit the number of hours an individual can work in a day or week, or may limit the type of job.

The informants judge their social acceptance by their inclusion in group activities. Several have felt accepted only in their adult years and two first experienced acceptance in activities designed specifically for the handicapped, indicating the importance of such programs. Informants who attended both integrated and segregated grade school settings generally report more acceptance in the segregated settings. College and university settings did not engender feelings of nonacceptance.

In leisure settings, accessibility remains a problem, with two informants reporting they did not feel total integration due to some social settings having restricted accessibility.

Age appropriate social skill development was difficult for some informants, at times, because they felt isolated , particularly in junior high school. One informant described a lengthy period when she had a very poor attitude because of a sudden loss of mobility.

A way to increase the socialization of handicapped persons is to provide information to them, such as a list of social gatherings which are accessible to the handicapped, or to provide a complete list of accessible social settings, such as restaurants and movie theaters in the areas in which they live. Such handbooks could be compiled by the disabled themselves and distributed by a variety of handicapped organizations or through disabled transportation systems, such as D.A.T.S.. These handbooks could grade social settings according to the accessibility into the building, accessibility of washroom facilities and accessibility to all areas in the setting. If there are problems the handbook could list those as well. When disabled individuals compile such guides, most or all of the relevant areas of accessibility will be looked at. Another method of providing information is through community papers and newspapers, in a special section in the classified advertisements. Handicapped persons are encouraged to determine social setting accessibility by telephoning and asking before going.

Basically, the informants attempt to lead lives as normal as possible. Several have completed some postsecondary education. Only one has not been employed. For most, more employment is an objective, with higher salary and less dependence on government assistance.

Disability type and degenerative condition have been central in the lives of the informants. Periods of stress included losses of mobility and periodic losses of body functions, a fact of life with some handicapping conditions. Counsellors may need to guide handicapped individuals through a mourning process to cope with these losses. Once the grieving process is at a manageable level, the counsellor may then help the handicapped individual develop realistic goals and objectives based on their new level of functioning. Handicapped individuals may also need guidance on how to handle everyday frustrations associated with their handicapping condition. Excessive frustration may lead to anger and resentment towards the rest of the world. The counsellor and the handicapped individual need to realize that some degree of frustration, anger and resentment is normal, but when carried to extremes may prevent individuals from achieving some form of normalcy in their life.

Implications for Counsellors

Counsellors and other professionals working with individuals who have visible differences need to decide with the client, if possible, the system or systems to be altered, which can vary with the age of the client. In childhood professionals may work primarily with external systems, including the family and school, and only secondarily with the individual system, inasmuch as the child can recognize the reality of the handicapping condition and has the ability to utilize coping skills. While medical persons work with the individual, explanations of needs may be made largely to parents and other adults involved in therapy. During adulthood the individual system will probably be the primary concern as it copes with external systems. Counsellors may need to work within other systems in order to facilitate chances necessary. A basic premise of systems counselling theory is that change in one system frequently affects other systems. How counsellors go about facilitating these changes may depend on the age of the client. For school aged children, the counsellor may interact with others who work with the child, such as school or medical personnel, or the child's family.

Before any intervention takes place a counsellor needs to have some understanding of the medical condition of the client, and the limitations and strengths involved. This will allow the counsellor to help the client or others to develop a realistic view of the handicapping condition.

A counsellor may provide guidance to the visible different child in different ways, depending upon the age of the child. A handicapped child may during the primary school years experience early recognition of difference in comparison to others. The counsellor may just need to listen to the child talk through these feelings of being different and how the child views this difference. The school counsellor may lead the chid to the realization that each person is not capable of doing everything, that each individual has capabilities which are unique.

Counsellors who work with visibly different children may need to work with medical and related services personnel so that accurate information can be provided to both parents and schools to assist in obtaining appropriate services for the child. As the child gets older and enters the adult years, counsellors may provide this information directly to the individual, as far as development and understanding allows, so that it can be incorporated within the planning and achievement of goals.

A counsellor who works with an adult who has a visible difference may work primarily within the individual system, assisting the client to clarify how external systems, such as family, social group, medical and related services and employment, influence the individual system. In young adulthood the counsellor may need to provide guidance for early moves toward independence. For some form of independence to be achieved both the individual and the counsellor may need to clarify current reasonable expectations. In order to achieve some of the goals set out the individual may need some type of support system and the counsellor may help the individual gain access to some of these services. Once the individual and the counsellor realize the limitations of the handicapped condition, reasonable goals can be selected.

Counsellors and other professionals may at times need to provide guidance for visibly different individuals with their social group interactions These professionals may need to help the handicapped individual develop social skills which will enable them to become part of a group, other than their family group. Counsellors may incorporate a variety of methods to achieve this goal. One method which may be used is assertiveness training, which not only may help the visibly different person develop some degree of confidence within social settings, but may help in developing the ability of how and where to ask for intervention and assistance. This may help individuals achieve more control over their own lives, something many visibly different individuals believe they do not have.

Advancements in Access and Their Implications

An area which has been alluded to in the interviews and in the discussion of the systems is the change in access, both to public settings and to programs. Fifteen years ago there was no Assured Income for the Severely Handicapped, allowing visibly different individuals who were unable to be employed little independence. Other changes which allow some visibly different individuals to live in the community instead of being institutionalized is the use of live-in aides who can be provided through government assistance, group homes and adapted transportation systems, allowing a greater amount of freedom.

The change in access can also be seen in public settings. Nowadays public buildings must be made accessible for individuals who use wheelchairs. Increased accessibility to buildings has allowed visibly different persons more access within the school and employment systems. Schools, university campuses and colleges are now adapted to give individuals who use wheelchairs an opportunity to attend, with ramps, elevators and wheelchair accessible washrooms. These changes also give more choices of employment for visibly different persons, as jobs which were once inaccessible may now be available because of access to the training required, and to the building where the employment opportunity is. Increased access to public buildings has also given visibly different individuals more opportunities to participate in and enjoy activities which have been accessible to nonhandicapped people, such as concerts, sporting events and shopping. Although the informants in this study do not directly acknowledge these changes, without them these individuals probably would not have achieved the level of independence they have, and participated in the community to the extent that they enjoy.

Implications for Further Research

This study is intended only as an initial look at the perceptions of visibly different young adults and how they cope with a handicapping condition in everyday life. It should be considered an initial look because only seven informants were interviewed. It is hoped future research will incorporate more participants in the study. Also, as this study had limited participants, the thirty to forty year age group was not included and future research could examine how individuals in their thirties cope with their visible differences. Another future consideration would be to study the perception of individuals who have varying types of handicapping conditions. This study only had informants who have visible differences, excluding the handicapping conditions of blindness and deafness. Further research could look at how these two groups of individuals cope with their handicapping condition and could investigate how individuals with invisible handicaps, such as epilepsy and diabetes, cope.

With respect to counselling, future research could look at providing information on successful interventions. Counsellors could then incorporate these successful interventions with appropriate counselling techniques, which can be looked at in further research. One appropriate counselling technique appears to be developing a sense of humor regarding the handicap. Many informants in this study mention using humor to cope with embarrassing moments which have arisen because of their handicap. Counsellors also need to give further attention to the role of the family in assisting the visibly different individual in the integration process. The family counsellor may need to assist the family and the older handicapped individual in redefining areas of responsibility in achieving the maximum level of independence for the handicapped person. Future research could look at developing appropriate counselling techniques for this area as well.

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APPENDIX A

THE CONSENT FORM

I am doing a Master's thesis in the Department of Educational Psychology, University of Alberta, on your perceptions of what you have found helpful in coping with your disability in ordinary life. I would like to discuss the following questions with you. You might like to read them over before we talk.

If any questions make you feel uncomfortable, we will leave them out. You can stop the interview at any time and opt out of the study if you wish to. Your name will not be used in the study, and total confidentiality will be maintained by using numbers, not names in the analysis of information.

If you do not object, it would help me if I could tape record our interview, to help maintain accuracy.

I ______________________________ agree to participate in the following study. I understand that total confidentiality will be maintained. I know that for whatever reason I may opt out at anytime. If I do not feel comfortable with any of the questions asked I can choose not to answer.

I agree
(circle one) to the tape recording of the interview
I do not agree

______________________ ______________________
(signature) (date)

APPENDIX B

THE INTERVIEW SCHEDULE

What is your age?
- sex?

Where did you grow-up?
- urban or rural setting, or a combination of both?

Where you grew up were there any special services available to help you or your family?
- if yes, what were they?

What is your disability?
- how long have you lived with your disability?
- prognosis?
- over the years do you feel your disability has improved in any way, remained stable, or deteriorated?
- how?
- why?

How do you think your coping skills in living with your disability has changed over the years?

Why do you think they have changed?

Do you think you are different from other people?

When did this first appear?

How did your family react?
- was their reaction(s) helpful or not helpful?
- why?

When you were growing up how did you feel about being different from others?

How did you cope with being different?

Other than your family, at what age did you feel you became part of a group?
- who was in this group?
- what activities did you do as a group?
- did you feel accepted by this group?
    - how?
    - why?

Throughout your life have you felt accepted by your social group?
- how?
- why?

In school did you feel accepted by your classmates?
- how?
- why?

Did you feel that your teachers accepted you?
- how?
- why?

Do you think that your teachers challenged you to your fullest potential?
- how?
- why or why not?

Did you go to school in an integrated school setting, a segregated school setting, or did your schooling entail a combination of both?
- grades?
- how many years in each setting?

How did you feel about this? (good or bad or indifferent)

Were there any people within the school setting who you considered to be helpful?

Who were your classmates? (disabled and nondisabled)

Were there other visibly different students in your class or in your school?

Overall, do you feel satisfied with the schooling you received?
- how?
- why or why not?

How far did you go in school?

What factors led you to continue to achieve a higher level of education?
(or discontinue school, or go back to school)

What activities did you participate in?
- in elementary?
- in secondary?
- in postsecondary?
    - with whom did you participate in these activities with?

Do you think your experiences in school helped or hindered your integration into society?
- how?
- why or why not?

While growing up were you hospitalized?
- if so, how often and for what reasons?
- how do you think these hospitalizations have affected you?

Were you satisfied with the way medical personnel treated you as a person?
- doctors
- nurses
- physios (physical therapists)
- occupational therapists (O.T.)
- speech therapists
- other (psychologists, social workers)

Did you find these people were helpful or not helpful with your integration into society?
- how?
- why or why not?

Who do you think has helped you to become integrated as a member of society?
- parents
- siblings
- other relatives
- teachers
- counsellors
- therapists (physio, O.T., speech)

How were they helpful? How were they not helpful?

Do you feel that you are an integrated member of society?
- how?
- why or why not?

Where do you live now?
(home, apartment, group home, institution)
- for how long?

Where have you lived previously?
(home, apartment, group home, institution)
- how long in each setting?
- how did you feel about each setting that you have lived in?

How do you like where you live now?

Do you feel any frustrations with your living arrangement?
- if so, how?
- why?

Do you live with anyone?
- if so, who?
- are there any frustrations?
- how do you deal or cope with them?

Do you have anyone come in and help you with any of your everyday chores? (cleaning, cooking, personal care)
- how do you feel about this?
- are there any frustrations with this arrangement?
- if so, what are they and how do you cope with them?

In terms of employment what jobs have you had?

Have you been satisfied with the jobs you have had?
- why?
- why not?

How do you find employers attitudes towards yourself and towards your disability?

Do you feel your disability has been a problem in any way for your employer? other co-workers? or do you feel that there is no problem?
- how?
- why or why not?

At anytime do you feel that you are being discriminated against in some way because of your disability?
- how?
- why?

How do you feel about this?

How do you cope with their difficulties regarding your disability?

In your social life do you find that your social group generally accepts you along with your disability?
- how?
- why?
- why not?

How does your social group show their acceptance? nonacceptance?

Are you satisfied with your group of friends?
- how?
- why?
- why not?

When you have been out with your friends have there been any embarrassing moments, which are connected somehow with your disability?
- if so, can you mention some

How do you handle these moments?

At anytime do you think your friends are uncomfortable with your disability?
- how?
- why?

What do you do to help your friends feel more comfortable with your disability?

When you are out in public how do you deal with uncomfortable moments which have arisen because of your disability?
- when you are alone?
- when you are with friends?

What do you do when you notice that people are uncomfortable around you?

How does it make you feel?

How do you deal with these feelings?

What are your daily challenges, frustrations in living with your disability?
- in your younger years (elementary school age)
- growing up (secondary school age, adolescence)
- young adulthood
- now

How do you cope with these frustrations? (now and in the past)
- have your coping skills changed throughout your life?
- if so, how?

Who was helpful in helping you learn to cope?

What do you think you have achieved so far?

What would you still like to achieve?